

## **Appendices**

### **Section 1 (pages 2-12)**

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## Section 1. Scleroderma survey (screenshots)

**DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA**

Section 1 of 5: Introduction Menu ▾

To thank you for your participation...

We are holding a draw for a 10.2-inch Apple iPad with Wi-Fi (32GB) (or Apple gift card of an equivalent value) for every 100 responses we receive, up to a maximum of 5 iPads (or gift cards).

If you would like to enter a draw for your chance to win, click on the button below. Or click on 'Next' to complete the survey without entering the draw.

[Click here to enter the draw](#)

Your personal information will be kept confidential and separate from your answers to the survey. This means that no one will be able to identify you. The information will be used only to contact you if you are a winner.

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**DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA**

Section 2 of 5: About Me Menu ▾

### Part 1. Demographic Questionnaire

In this first part, we are going to ask you some general questions about you and your health.

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**DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA**

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What type of scleroderma do you have?

Diffuse (systemic) scleroderma/scleriosis

Limited scleroderma - CREST Syndrome

Other(s) (please specify)

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**DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA**

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How old are you? Please click in the box and enter your age.

years old

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**DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA**

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What is your gender?

Woman

Men

Gender-fluid, non-binary, and/or Two-Spirit

Prefer not to say

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DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

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How old were you when you were clinically diagnosed with scleroderma?

 years old

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What country do you live in? Please select **all that apply**.

Canada

Other (please specify)

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In which province or territory do you live?

Alberta

British Columbia

UBC mail   
<https://www.mail.ubc.ca/owa/auth/login.aspx?re...>

New Brunswick

Newfoundland and Labrador

Northwest Territories

Nova Scotia

Nunavut

Ontario

Prince Edward Island

Quebec

Saskatchewan

Yukon

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

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In which province or territory do you live?

- |                           |                       |
|---------------------------|-----------------------|
| Alberta                   | <input type="radio"/> |
| British Columbia          | <input type="radio"/> |
| Manitoba                  | <input type="radio"/> |
| New Brunswick             | <input type="radio"/> |
| Newfoundland and Labrador | <input type="radio"/> |
| Northwest Territories     | <input type="radio"/> |
| Nova Scotia               | <input type="radio"/> |
| Nunavut                   | <input type="radio"/> |
| Ontario                   | <input type="radio"/> |
| Prince Edward Island      | <input type="radio"/> |
| Quebec                    | <input type="radio"/> |
| Saskatchewan              | <input type="radio"/> |
| Yukon                     | <input type="radio"/> |

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

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Do you live in a remote, rural, or metropolitan area?

- |              |                       |
|--------------|-----------------------|
| Remote       | <input type="radio"/> |
| Rural        | <input type="radio"/> |
| Metropolitan | <input type="radio"/> |

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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How do you identify? Please select **all that apply**.

- |                                   |                       |
|-----------------------------------|-----------------------|
| Aboriginal or indigenous          | <input type="radio"/> |
| African American or Black         | <input type="radio"/> |
| Asian                             | <input type="radio"/> |
| Caucasian                         | <input type="radio"/> |
| Hispanic or Latino(a)             | <input type="radio"/> |
| South Asian                       | <input type="radio"/> |
| How I identify is not listed here | <input type="radio"/> |
| Prefer not to say                 | <input type="radio"/> |

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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What kind of healthcare coverage do you **currently** have? Please select **all that apply**.

Public health insurance (i.e. you are covered by insurance run by, or on behalf of, your national, regional or provincial government)

Private insurance through an employer

Individual private insurance

None (I would pay out of pocket for medical costs)

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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What is your approximate **annual** household income?

Please click on the box to enter a number, then select the currency in the box to the right. If you prefer not to answer, you can skip this question by clicking on "Next".

Note: By **annual household income** we mean the total annual income from all people in your household, after taxes.

Currency (select):

- Canadian Dollar (\$)
- Australian Dollar (\$)
- US Dollar (\$)
- Euro (€)
- Mexican Peso (\$)

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

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How many people are in your household?

 people

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Section 2 of 5: About Me

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How much do you normally pay out of pocket **each year** toward the cost of your scleroderma/CREST syndrome for **any medical expenses**?

Please use the currency you selected in the previous question. Enter '0' if you do not pay anything. If you prefer not to answer, you can skip this question by clicking on "Next".

 \$ / €

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

Menu -

How much do you normally pay out of pocket **each year** toward the cost of your scleroderma/CREST syndrome for **any travel and accommodation**?

Please use the currency you selected in the previous question. Enter '0' if you do not pay anything. If you prefer not to answer, you can skip this question by clicking on "Next".

 \$ / €

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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How much do you normally pay out of pocket **each year** toward the cost of your scleroderma/CREST syndrome for **any other expenses (please specify)**?  
Please use the currency you selected in the previous question. Enter '0' if you do not pay anything. If you prefer not to answer, you can skip this question by clicking on "Next".

Note: **Any other expenses** refer to additional, medical and non-medical expenses related to your scleroderma/crest such as alternative medicine, wellbeing, childcare to attend medical appointments. In the next page you will be asked to specify what expenses you have considered.

 \$ / €

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

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Please specify what your **other expenses** include:  
If you did not have any other expenses, please enter 'I don't have any other expenses' or enter '0'.

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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How far do you have to travel to see your main specialist (e.g. rheumatologist) for the care of your scleroderma/CREST syndrome?  
Please click on the box to enter a number, then select the unit of length in the box to the right.

 Kilometres  
Miles

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

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Do you lose income due to attending appointments for the care of your scleroderma/CREST syndrome?

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

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Do any family members/friends lose income due to attending appointments for the care of your scleroderma/CREST syndrome?

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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Have you had to forgo any expenditures in the last year in order to afford the cost of your medical care for scleroderma/CREST syndrome (e.g. education, food, etc.)?

Yes

No

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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### Part 2. Learning about stem cell transplant as an option to treat diffuse scleroderma

Before we ask you about your preferences for stem cell transplant, we are going to give you some information about stem cell transplant and ask you to answer knowledge questions about what you have read. This is so we can see if we are communicating the information well.

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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### General information about Stem Cell transplant

Stem cell transplant is a relatively recent option for people with diffuse scleroderma and although it is already offered in some centers in Canada, research is still underway to uncover the full potential of the therapy.

Stem cells are collected from a person's blood, the person then receives chemo- and sometimes radiotherapy to eliminate their dysfunctional immune system and then the stem cells are re-introduced into the person's body to help rebuild a healthy immune system.

The treatment requires a long hospital stay of one month, and about four additional months of staying in the hospital's proximity as an outpatient for monitoring.

For example, currently eligible patients in British Columbia are being offered treatment in Calgary, which typically means a 5 month stay away from their home. In addition, follow-up visits are required 6 months, one year and then annually after the transplant.

#### True or False:

Same people who receive stem cell transplant for scleroderma are discharged and can go home in the week after the treatment.

True

False

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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### The benefits that people might expect after being treated with stem cell transplant?

People who are diagnosed with diffuse scleroderma face a high risk of their organs becoming affected, which in turn affects their life expectancy. Because stem cell transplant gives the person new blood cells, the immune system is 'rebooted' to stop the progression of scleroderma.

This means that after treatment, although there may be some residual symptoms of the disease, the disease can go into remission for a long time. If this happens, it is expected that the person will live longer.

#### True or False:

Stem cell transplant might increase the life expectancy of a person who was diagnosed with diffuse scleroderma.

True

False

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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### The risks that people might expect after being treated with stem cell transplant?

Stem cell transplant might lead to serious complications.

The most severe complication is death of the person undergoing treatment, generally from infection or side effects of the drugs. During stem cell transplant, the immune system is 'shut-down' so it can be 'rebooted'. If during this process the person becomes ill with an infection, the person's body might not yet be able to fight the infection and the person might die.

Also, the drugs used to 'shut-down' the immune system can be very toxic and lead to serious organ (lung and heart) damage.

Other, non-life-threatening, complications of getting a stem cell transplant include anaemia (low red blood cell count), bleeding, feeling tired and run down. These are likely to go away as your body recovers from the treatment, but can last several months.

#### Which one is correct?

There are no risks of serious complications after stem cell transplant

Only older people can get infections after receiving stem cell transplant

Infection is one of the main serious complications of stem cell transplant and it can be fatal

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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### What other treatments people can expect after being treated with stem cell transplant?

People who receive stem cell transplant need to go through chemotherapy.

The best treatment approach for stem cell transplant to treat diffuse scleroderma in Canada has not yet been decided.

There are two main approaches:

1. one uses a lower intensity of chemotherapy in addition to total body radiotherapy (irradiation);
2. the other uses chemotherapy only, though at a higher intensity.

Adding radiotherapy allows the elimination of the diseased immune cells more completely, but also suppresses the immune system more, leaving the body more vulnerable to infections and eventually some forms of cancer.

In addition to infection and serious organ damage, side effects from chemotherapy include loss of fertility, difficulty eating and drinking after the treatment, diarrhoea and profound fatigue.

#### Which of the following treatment options might be offered to treat diffuse scleroderma:

Stem cell transplant only

Stem cell transplant and immune-suppressants

Stem cell transplant, chemotherapy, total body radiotherapy and immune-suppressants

Stem cell transplant, total body radiotherapy and immune-suppressants

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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### Who is a candidate for stem cell transplant?

Diffuse cutaneous systemic sclerosis is a more severe type of scleroderma which causes hardening of the skin and leads to problems with one or more of your organs (heart, lungs and kidneys).

In addition to the symptoms of limited scleroderma or CREST, it is also more common to experience pain and fatigue and have trouble breathing whilst doing daily activities.

Candidates for stem cell transplants, based on current criteria typically:

- Are aged between 18 and 65 years
- Have very quickly developing scleroderma which has progressed within 4 years to diffuse cutaneous systemic sclerosis, defined by:
  - Problems with one or more of your heart, lungs and kidneys
  - Skin hardening (fibrosis)

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 2 of 5: About Me

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### Part 3. Your preferences for stem cell transplant

In this part of the survey we will ask you to choose between different treatment options to try to understand what features of stem cell transplant are important to you.

In the survey, each treatment will be described by the following features:

- + 1. Years after treatment without further scleroderma organ damage
- + 2. Immune suppression treatment and risk of immediate complications which could lead to death
- + 3. Risk of late complications (i.e. cancer)
- + 4. Additional members to your care (in addition to your rheumatologist)
- + 5. Number of people with scleroderma the hematologist has treated using stem cell transplant
- + 6. Additional cost to you (expenses not covered by the provincial health plan, nor your health insurance)
- + 7. Additional distance of treatment center to your home

First, you will see an example of the choice task, then we present you with **2 different** choices for you to pick your preferred treatment. You will see more instructions in the next pages.

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 3 of 5: My Values

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### About this part of the survey

To answer this part of the survey, we would like you to imagine that you have had diffuse cutaneous systemic sclerosis for 3 years and are a candidate for stem cell transplant.

**We will show you 12 scenarios.** Please consider each scenario as if you were being offered treatment A and B and as if you were choosing between them in the **real world**.

Then we will ask you to tell us **which treatment A or B that you most prefer**.

Although **these choices will look similar, and may feel repetitive, the features of stem cell transplant A and B will be different each time.**

You can state that you **do not prefer either treatment by choosing 'No stem cell transplant'** (I would not choose any of the treatments).

**Choosing 'No stem cell transplant'** means that you would continue with your current treatment, which would likely be a drug which suppresses the immune system like mycophenolate, cyclophosphamide, or methotrexate.

**You will now be asked to make 12 choices.** An example of a scenario is shown on the next page, before you make the 12 choices.

**There are no right or wrong answers, just pick which you prefer!**

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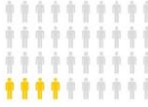
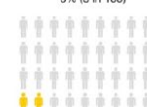


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DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Imagine that you have had diffuse cutaneous systemic sclerosis for 3 years and are a candidate for stem cell transplant.

Which treatment do you prefer?

Question 1 of 12

	Stem cell transplant A	Stem cell transplant B	No stem cell transplant
<b>Years after treatment without further scleroderma organ damage</b> ⓘ	5 years	2 years	1 year
<b>Immune suppression treatment and risk of immediate complications</b> ⓘ	<p><i>Chemotherapy:</i></p> <p>Risk of complications which could lead to death:</p> <p>10% (10 in 100)</p>  <p><a href="#">Click here for more information</a></p>	<p><i>Low dose chemotherapy and full body irradiation:</i></p> <p>Risk of complications which could lead to death:</p> <p>5% (5 in 100)</p>  <p><a href="#">Click here for more information</a></p>	No additional risk of immediate complications
<b>Late complications (i.e. cancer)</b> ⓘ	<p>Risk of late complication from treatment (e.g. cancer) <b>in the future:</b></p> <p>20% (20 in 100)</p>  <p><a href="#">Click for more information</a></p>	<p>Risk of late complication from treatment (e.g. cancer) <b>in the future:</b></p> <p>5% (5 in 100)</p>  <p><a href="#">Click for more information</a></p>	No additional risk of late complications
<b>Team care (in addition to the standard medical care)</b> ⓘ	No additional team members	<p>Extended medical team:</p> <ul style="list-style-type: none"> <li>• Rheumatologist</li> <li>• Hematologist</li> <li>• Cardiologist</li> <li>• Respirologist</li> <li>• Nurse</li> </ul>	No additional team members
<b>Number of people with scleroderma the hematologist has treated using stem cell transplant</b> ⓘ	5 or more patients	5 or more patients	No information
<b>Additional cost to you (expenses not covered by the provincial health plan, nor your health insurance)</b> ⓘ	\$5,000 - \$10,000	\$1,000 - \$5,000	No additional costs
<b>Additional distance of treatment center to your home</b> ⓘ	Between 50 and 300 km	Between 300 and 1,000 km	0 km

Which treatment do you prefer?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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[Reset this question](#)

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 4 of 5: How you rate your health

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### Part 4. Your health and quality of life

Thank you for telling us what treatments you would prefer.

In this last part of the survey, we are going to ask you some questions about your health and quality of life.

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 4 of 5: How you rate your health

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1. In general, would you say your health is:

Excellent

Very good

Good

Fair

Poor

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 4 of 5: How you rate your health

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2. Compared to one year ago, how would you rate your health in general now:

Much better

Somewhat better

Same

Somewhat worse

Much worse

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 4 of 5: How you rate your health

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Do you have any thoughts about the survey you would like to share with us?

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 4 of 5: How you rate your health

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Did any of the questions or content impact you in any way?

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## DECISION MAKING IN STEM CELL TREATMENT FOR SCLERODERMA

Section 5 of 5: Summary

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Thank you for participating in our study!  
You may now close this window.

[Learn more about the BC Support Unit and HESM](#)

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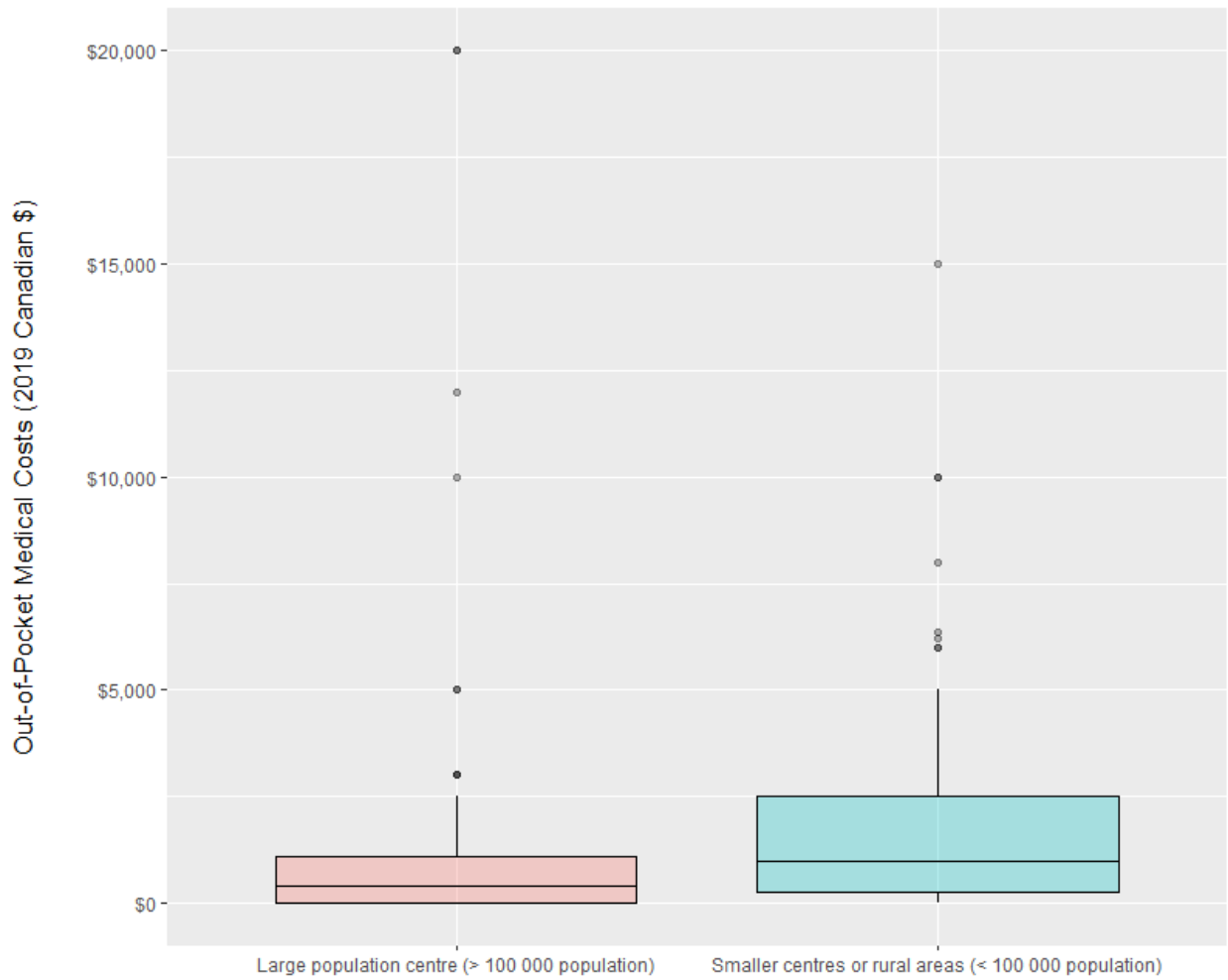
## Section 2. GRIPP2-Short Form Checklist for the Reporting of Patient Engagement in Research

Section and Topic	Item
1. Aim	<p><i>Report the aim of PPI in the study.</i></p> <p>Researchers and Canadian patients with scleroderma co-developed and distributed an international online survey to understand the preferences of people with scleroderma for autologous stem-cell transplant treatment. Based on their own personal experience living with Scleroderma, the patient partners identified a need to better understand the burden in accessing care and treatment. As a first step, the patients wanted to understand how the financial out-of-pocket costs associated with treatment. This included medical, non-medical, and travel and accommodation costs. Further, through their lived experience the patient partners recognized that this burden is likely exacerbated for those living in smaller communities and wanted to estimate the extent of this inequity.</p>
2. Methods	<p><i>Provide a clear description of the methods used for PPI in the study</i></p> <p>Throughout the research process, patient partners and researchers met several times per year through teleconference meetings and communicated regularly through email. The survey was co-developed by the patient partner and researchers, including the questions related to cost. The patient partners reviewed the online survey and provided feedback to ensure the questions were clear and accessible. After data collection was complete, the patient partners supported the analysis and interpretation of the data. They also contributed to writing of the manuscript, particularly in putting the findings within the broader literature and understanding the implications for policy makers</p>
3. Study Results	<p><i>Outcomes—Report the results of PPI in the study, including both positive and negative outcomes</i></p> <p>Patient partners contributed by identifying the research question, developing the survey, including the specific questions related to and cost. Further, they reviewed the results and provided important information to outline the policy implications. Patient partners also help write and subsequently review this final manuscript and chose the target journal.</p>
4. Discussion and Conclusions	<p><i>Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects.</i></p> <p>The patient partners were the driving force in conducting this research which lends credibility to the findings. It was their input that led to the inclusion of questions related to cost, and their idea to approach this question with an equity lens. Furthermore, the policy insight through work with the Scleroderma society helped us shape the findings in a way that is relevant to policy makers, in particular thinking about the implications for virtual care which is a key policy priority given the pandemic.</p>
5. Reflections/critical perspective	<p><i>Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience.</i></p>

	<p>Our sample appears to be representative of the Canadian scleroderma community based on demographic and clinical characteristics (gender and age) when compared with a prior survey. However, due to our recruitment strategy our sample came almost exclusively from three Canadian provinces. As such, our results may not be representative of all Canadians.</p> <p>Despite being open for several months, we received only 120 Canadian respondents to the survey. This may reflect that this analysis was only one part of a larger survey that included questions related to treatment preferences. As a result of the sample size, we dichotomized the indicator for community size (small vs large) which may mask some important differences in cost, particularly for those living in rural/remote communities.</p> <p>Despite these challenges, this is the first Canadian study to provide an estimate of the burden to access care for those living with Scleroderma. This was a research question identified by patients and can be used to inform future research to improve outcomes and equity.</p>
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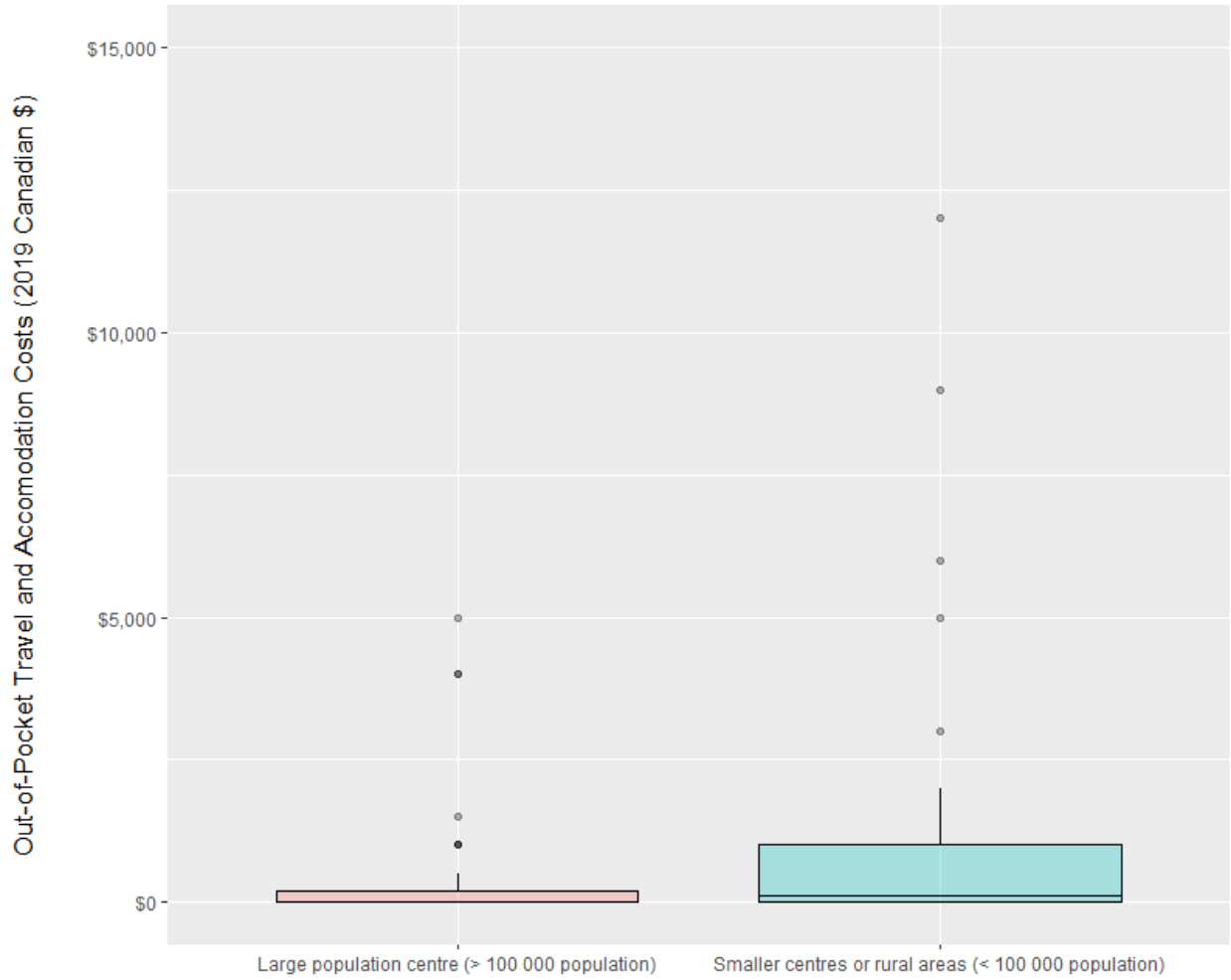
### Section 3.

#### Boxplots of the distribution of out-of-pocket “medical costs” by community size

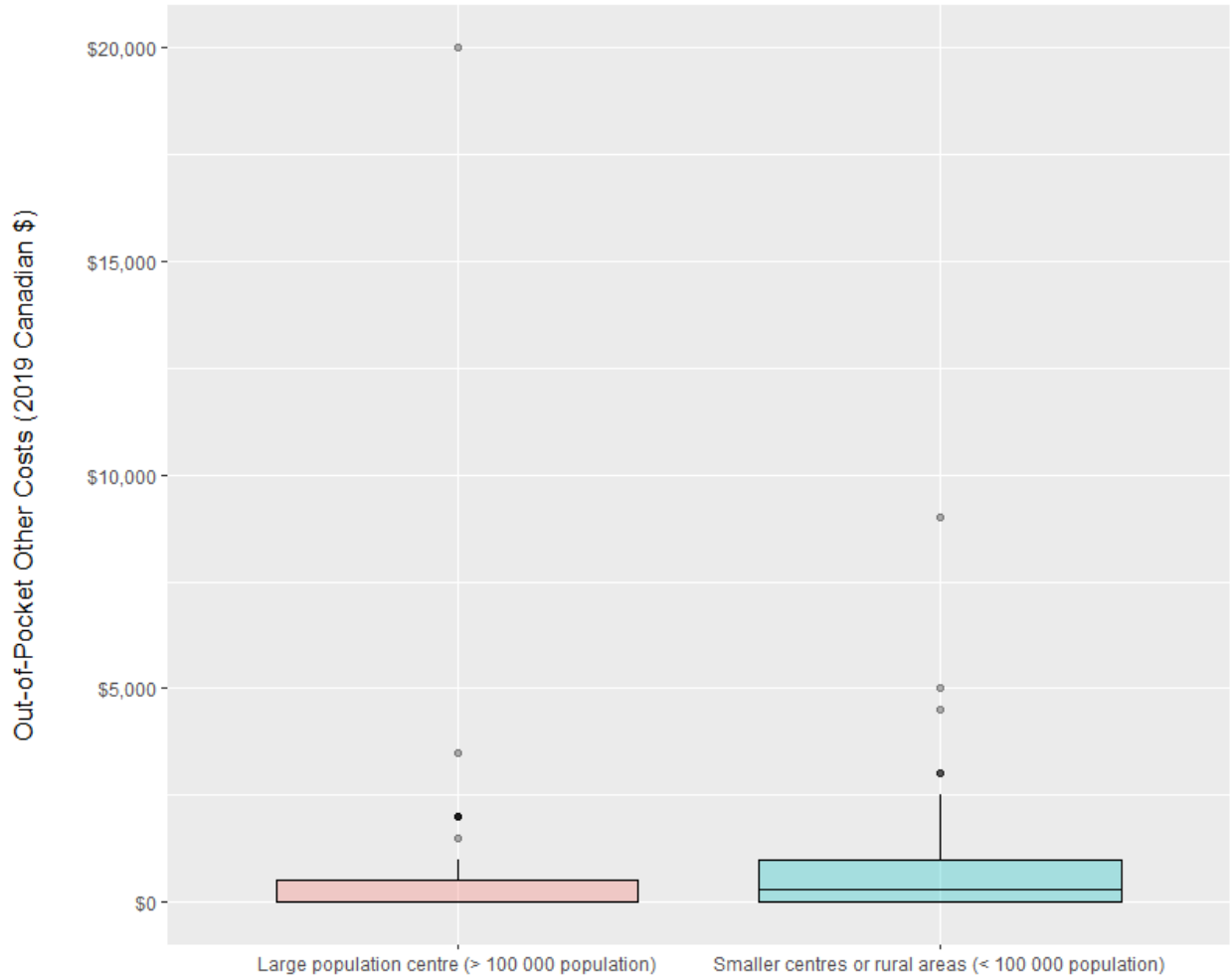




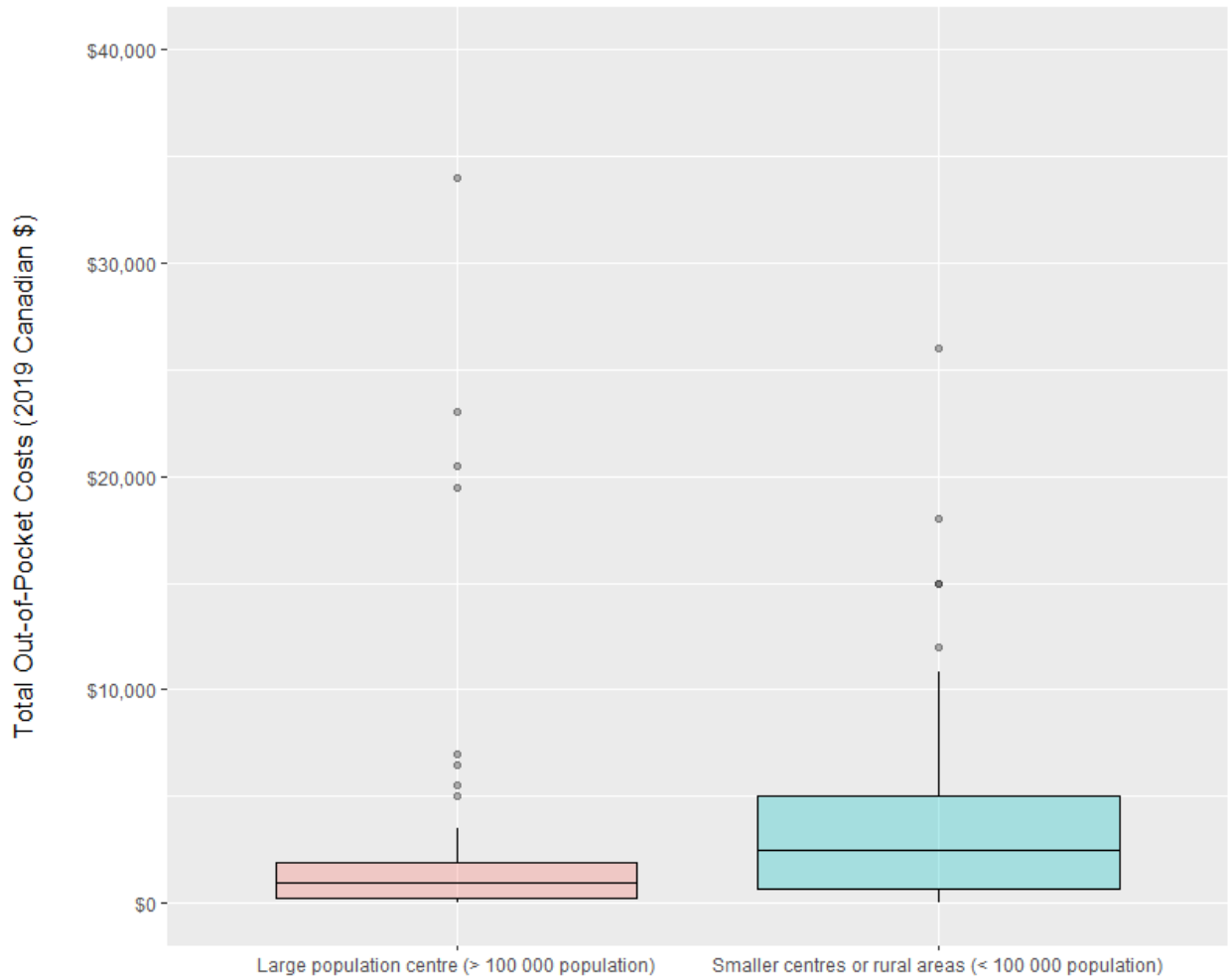
**Boxplots of the distribution of out-of-pocket “travel and accommodation” costs by community size**



### Boxplots of the distribution of out-of-pocket “other” costs by community size



### Boxplots of the distribution of “total” out-of-pocket costs by community size



#### Section 4. Exponentiated regression coefficients and confidence intervals [CI]s for multivariate models exploring the relationship between community size and out-of-pocket costs

	Total Costs		Medical Costs		Travel/Accommodation Costs		Other Costs	
	<i>logistic: OR [CI]</i>	<i>glm: exp<sup>β</sup> [CI]</i>	<i>logistic: OR [CI]</i>	<i>glm: exp<sup>β</sup> [CI]</i>	<i>logistic: OR [CI]</i>	<i>glm: exp<sup>β</sup> [CI]</i>	<i>logistic: OR [CI]</i>	<i>glm: exp<sup>β</sup> [CI]</i>
<b>Community Size</b>								
Large Urban Centre ≥100k ( <i>reference</i> )	-	-	-	-	-	-	-	-
Smaller Urban Centre or Rural Area <100k	2.19 [0.77-6.64]	1.53 [0.77-3.01]	<b>3.56 [1.51-8.86]</b>	0.83 [0.39-1.75]	2.17 [0.99-4.87]	<b>2.77 [1.14-6.27]</b>	1.78 [0.81-4.00]	0.96 [0.36-2.47]
<b>Age (per decade)</b>	0.78 [0.48-1.24]	0.93 [0.68-1.27]	0.68 [0.45-1.01]	1.2 [0.86-1.66]	0.77 [0.53-1.10]	0.90 [0.63-1.29]	0.82 [0.57-1.17]	0.85 [0.51-1.37]
<b>Gender</b>								
Female ( <i>reference</i> )	-	-	-	-	-	-	-	-
Male	0.50 [0.14-2.08]	0.91 [0.37-2.71]	0.53 [0.16-1.77]	1.26 [0.46-4.18]	0.38 [0.11-1.19]	3.04 [0.81-17.14]	0.35 [0.10-1.10]	0.95 [0.22-7.23]
<b>Household Income (per \$1,000)</b>	1.01 [0.97-1.06]	0.97 [0.95-1.00]	0.99 [0.96-1.02]	0.97 [0.95-1.01]	<b>0.96 [0.91-0.99]</b>	0.99 [0.96-1.04]	0.96 [0.91-1.00]	1.00 [0.93-1.09]
<b>Scleroderma Type</b>								
Limited ( <i>reference</i> )	-	-	-	-	-	-	-	-
Diffuse/Other	2.02 [0.72-5.97]	1.27 [0.68-2.36]	1.37 [0.59-3.25]	1.35 [0.71-2.55]	0.76 [0.35-1.66]	1.18 [0.55-2.57]	1.62 [0.74-3.61]	0.89 [0.33-2.32]
<b>Self-reported Health</b>								
Excellent; Very Good; Good ( <i>reference</i> )	-	-	-	-	-	-	-	-
Fair; Poor	0.46 [0.20-1.19]	0.53 [0.18-1.57]	0.47 [0.19-1.35]	1.14 [0.40-3.33]	0.92 [0.37-2.91]	0.5 [0.17-1.42]	0.76 [0.19-4.29]	0.46 [0.20-1.19]
Observations	120	101	120	83	120	62	120	60

OR: odds ratio; glm: generalized linear model; CI: confidence interval