GRIPP2-Short Form Checklist for the Reporting of Patient Engagement in Research

| Section and Topic | Item | Reported on lines |
|---|---|---|
| 1. Aim | *Report the aim of PPI in the study.*<br><br>Researchers and Canadian patients with scleroderma co-developed and distributions 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. | Page 4<br>Paragraph 4 |
| 2. Methods | *Provide a clear description of the methods used for PPI in the study*<br><br>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 | Page 5<br>Paragraph 3 |
| 3. Study Results | *Outcomes—Report the results of PPI in the study, including both positive and negative outcomes*<br><br>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. | Page 6<br>Paragraphs 3 and 4 |
| 4. Discussion and Conclusions | *Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects.*<br><br>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 | Page 6<br>Paragraph 5 |

| | | |
|---|---|---|
| | 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. | |
| 5. Reflections/critical perspective | *Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience.*<br><br>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.<br><br>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.<br><br>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. | Page 7 Paragraphs 1-4 |