

Table S1. Consolidated Criteria for Reporting Qualitative Research (COREQ)**COREQ (CONSOLIDATED criteria for REporting Qualitative research) Checklist**

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials (eg, PhD, MD)?	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher (eg, personal goals, reasons for doing the research)?	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator (eg, bias, assumptions, reasons and interests in the research topic)?	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study (eg, grounded theory, discourse analysis, ethnography, phenomenology, content analysis)?	
<i>Participant selection</i>			
Sampling	10	How were participants selected (eg, purposive, convenience, consecutive, snowball)?	
Method of approach	11	How were participants approached (eg, face-to-face, telephone, mail, email)?	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected (eg, home, clinic, workplace)?	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample (eg, demographic data, date)?	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified (eg, participant number)?	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357. doi:10.1093/intqhc/mzm042

Table S2. Purposive Sampling Criteria

Gender	Visible minority status	Education level	Household income	Household composition	EDSS	Transition stage
Cis-gender female	Self-reported visible minority	Elementary: grade 5-8	Self-reported > \$42,000	Parents	< 3.0	At pediatric center (SickKids)
Cis-gender male	Self-reported not visible minority	High school: grade 9-12	Self-reported < \$42,000	Single parent	> 3.0	At adult center after transfer from pediatric
Self-identified as a gender other than cis-gender male or female		University or college		Alone		Always been at adult center (St. Michael's)
				Roommate		

EDSS, Expanded Disability Status Scale.

Note: We aimed to recruit a similar number of participants whose gender self-identification was boy/man and girl/woman, and at least 1 youth who self-identified as a gender other than boy/man or girl/woman. We also aimed to purposefully sample participants with

varied visible minority status, education level, household income, household composition, and EDSS scores, with at least 1 participant in each category. Lastly, we aimed to recruit a similar number of participants from pediatric and adult centers, and at least 1 participant who had always been at an adult center.

Table S3. Participant Interview Guide

Here are some of the questions you will be asked in the interview. Please note that, depending on your answers, the researcher may ask you additional related questions to learn more.

1. What is it like for you to have multiple sclerosis (MS)?
2. How does having MS impact your life?
3. What does a normal day look like for you?
4. How do you take care of your life with MS?
5. What does it mean to you to take care of your life and life with MS? How does it look when you are taking care of your MS? How does it look when you are not?
6. What life changes are you experiencing or expecting to experience in the next few years? How do you think your MS may impact those changes?
7. What do you think it's going to be like at the adult clinic? What are you excited about? What are you worried about? What do you think will help you prepare for this move? OR What has it been like at the adult clinic? What were you excited about? What were you worried about? What do you think helped you prepare for this move?

Table S4. Interview Guide

QUESTIONS

PROMPTING QUESTIONS

What is it like for you to have multiple sclerosis (MS)?

- How long have you had MS?
- What kind of symptoms do you have?
- What medication(s) do you take for MS, if any?
- How do you feel about having MS?

What does a normal day look like for you?

- What are all the things you do in the morning before you go to school or work?
- What does the day look like at school or work?
- What about after school or work? Before bed?
- How are things different over the weekend?
- What aspects of your day change when you have symptoms of MS?

How does having MS impact your life?

- How does having MS impact your life at home? At school? At work?
- How does MS impact your life with family? Siblings? Friends?
- How does MS impact what you like to do for fun with family? Friends? By yourself?

What does it mean to you to take care of your life and life with MS? How does it look when you are taking care of your MS? How did you learn this?

- *If the participant asks what we mean by “taking care of your MS,” we share the following definition: The ability to take care of symptoms, treatment, and physical, emotional, and social results of having MS. Taking care of your MS also may include lifestyle changes due to living with a chronic condition.*

How does it look when you are not?

- Are you part of any clubs/MS Society groups/internet groups that help you with your life with MS?
- Do you have friends with MS who help you take care of your life with MS?

What lifestyle changes have you experienced or are you experiencing or expecting to experience in the next few years? How do you think your MS will impact those changes?

- Are you going to get a job? Go to university?
- Move out/move away?
- Start driving?
- Start dating?
- Start family planning?

For SickKids participants:

What do you think it's going to be like at the adult clinic? What are you excited about? What are you worried about? What do you think will help you prepare for this move?

- How do you think things will change with having a new doctor?
- How do you think things will change being in an adult hospital?
- How do you think medications, appointments, and bloodwork will be different?

For St. Michael's Hospital participants:

What has it been like at the adult clinic? What were you excited about? What were you worried about? What do you think helped prepare you for this move?

- How do you think things have changed with having a new doctor?
- How do you think things have changed since being in an adult hospital?
- How were medications, appointments, and bloodwork different?

Table S5. Patient-Partner Training Resources

1. Patient-Oriented Research Curriculum in Child Health training modules for patients and families: <https://porcch.ca/>

2. The Tri-Council Policy Course on Research Ethics: https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2022.html
3. Selected sections from: How-to-Guide for Patient Engagement in Research Training Program (CIHR- Institute of Musculoskeletal Health and Arthritis Modules): <https://cihr-irsc.gc.ca/e/27297.html>
4. Patient Engagement in Health Research: A How-to Guide for Researchers (Alberta SPOR Support Unit): <https://absporu.ca/resource/patient-engagement-in-health-research-a-how-to-guide-for-researchers/>
5. Selected videos: Dr. J Thesising 101 (thematic analysis series): <https://www.youtube.com/watch?v=67L3P4sd6w0&t=521s>
6. Selected videos: E-Learning Qualitative Methods from the Centre for Critical Qualitative Health Research, University of Toronto: <https://ccqhr.utoronto.ca/resources/videos/>
7. Selected passages: Thorne SB. *Interpretive Description: Qualitative Research for Applied Practice*. 2nd ed. Routledge; 2016.
8. Selected passages: Creswell JW, Poeh CN. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. 4th ed. Sage Publications; 2017.