

Appendix e-1. Full survey questions

Part I: Clinical Trial Expectations

1a. To what extent do you agree with the following statements?

My reasons for participating in the CCSVI trial were...	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
To advance understanding or treatment of MS	1	2	3	4	5
To help prove that the procedure is safe	1	2	3	4	5
To help prove that the procedure is effective in treating MS	1	2	3	4	5
This was the only way I could get the procedure in Canada	1	2	3	4	5

1b. To what extent do you agree with the following statements?

When I entered the study I expected that the CCSVI procedure would...	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Cure MS - reverse all functional loss and existing symptoms and prevent future attacks and symptoms	1	2	3	4	5
Partially reverse MS - reverse some functional loss and existing symptoms	1	2	3	4	5
Halt MS progression – stop disease progression	1	2	3	4	5
Slow down MS progression – slow down disease progression, make attacks less frequent	1	2	3	4	5
Have no impact on MS – have no improvement in disease course or symptoms	1	2	3	4	5

1c. My expectations about the degree of medical benefit that the CCSVI procedure would provide me were met.

Not at all met	Slightly met	Somewhat met	Moderately met	Completely met
1	2	3	4	5

Part II: Clinical Trial Process

PLEASE ALLOW PARTICIPANT TO INDICATE ONLY ONE ANSWER PER QUESTION AND CLEARLY MARK THEIR ANSWER BY CIRCLING THE CORRESPONDING NUMBER.

2. To what extent do you agree with the following statements?

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The study was explained to me thoroughly	1	2	3	4	5
I feel that I understood the study process	1	2	3	4	5
I believe that the use of two procedures (one sham and one actual procedure) was necessary to generate credible results	1	2	3	4	5
I believe that any discomfort from the two procedures (one sham surgery and one CCSVI procedure) was an appropriate trade-off to generate credible science	1	2	3	4	5
I believe that the use of two procedures (one sham surgery and one CCSVI procedure) promoted fairness in the study	1	2	3	4	5

Part III: Additional Questions

PLEASE ALLOW PARTICIPANT TO INDICATE ONLY ONE ANSWER PER QUESTION AND CLEARLY MARK THEIR ANSWER BY CIRCLING THE CORRESPONDING NUMBER.

3. Where have you received information about CCSVI?

I have received information about CCSVI from...	No information	A little information	Some information	A lot of information	Primary source of information
Traditional media outlets – TV, newspaper (print or online)	1	2	3	4	5
Social Media – Facebook, Twitter	1	2	3	4	5
Healthcare providers – family physician, neurologist, physiotherapist	1	2	3	4	5
Other patients – in person, advocacy groups, blogs	1	2	3	4	5
Friends/family	1	2	3	4	5
Internet – WebMD, forums, advertisements	1	2	3	4	5

4a. Are you familiar with the strong opinion among the Canadian medical community that ongoing research on the CCSVI procedure is no longer needed?

Not at all familiar	Slightly familiar	Somewhat familiar	Moderately familiar	Completely familiar
1	2	3	4	5

4b. If you are familiar with the option noted above (your answer for question 4a was greater than 1), was your decision to participate or continue to participate in this study discouraged by the views of the Canadian medical community about the CCSVI procedure?

Not at all discouraged	Slightly discouraged	Somewhat discouraged	Moderately discouraged	Extremely discouraged
1	2	3	4	5

5. Does the experience of participating in this study influence your interest in participating in future research to advance understanding or treatment of MS?

Strongly discourages future participation	Discourages future participation	No impact on future participation	Encourages future participation	Strongly encourages future participation
1	2	3	4	5

6. Do you believe that important scientific knowledge will be gained as a result of this study?

Not at all	Slightly	Somewhat	Moderately	Highly
1	2	3	4	5

7. Government funds were used to support this study. Do you believe that this was an appropriate use of tax dollars?

Not at all appropriate	Slightly inappropriate	Neutral	Slightly appropriate	Absolutely appropriate
1	2	3	4	5

8. Do you believe that further research is necessary to determine the safety and effectiveness of the CCSVI procedure?

Not sure	Not at all necessary	Somewhat necessary	Moderately necessary	Extremely necessary
1	2	3	4	5

Part IV: Demographic Information

PLEASE ALLOW PARTICIPANT TO INDICATE ONLY ONE ANSWER PER QUESTION AND CLEARLY MARK THEIR ANSWER BY FILLING IN THE CORRESPONDING BOX.

9. What is the highest level of education that you have completed?

- ☐ High school
- ☐ Trade school
- ☐ College
- ☐ University
- ☐ Post-university advanced degree (e.g., MSc, MD, PhD)
- ☐ Prefer not to answer

10. What is your annual household income:

- ☐ Less than \$19,999
- ☐ \$20,000 to \$39,999
- ☐ \$40,000 to \$59,999
- ☐ \$60,000 to \$79,999
- ☐ \$80,000 to \$99,999
- ☐ \$100,000 to \$149,999
- ☐ \$150,000 or more
- ☐ Prefer not to answer

Appendix e-2. Full dataset for questions at both time points

Question	Timepoint	Response				
		1	2	3	4	5
1ai	Survey 1	0	1	4	17	41
	Survey 2	0	0	1	16	46
1aii	Survey 1	1	3	7	25	27
	Survey 2	3	2	10	21	27
1aiii	Survey 1	1	3	11	18	30
	Survey 2	1	2	14	21	25
1aiv	Survey 1	6	3	21	11	22
	Survey 2	3	6	9	16	29
1bi	Survey 1	19	17	24	3	0
	Survey 2	22	15	20	5	1
1bii	Survey 1	2	11	17	31	2
	Survey 2	8	8	17	26	4
1biii	Survey 1	2	21	20	17	3
	Survey 2	5	22	19	13	4
1biv	Survey 1	2	7	15	34	5
	Survey 2	5	10	19	22	7
1bv	Survey 1	6	22	26	6	3

	Survey 2	15	14	21	8	5
1c	Survey 1	11	5	16	15	16
	Survey 2	10	6	22	11	14
2i	Survey 1	0	0	1	17	45
	Survey 2	0	2	1	13	47
2ii	Survey 1	0	0	2	21	40
	Survey 2	0	1	2	19	41
2iii	Survey 1	0	2	0	21	40
	Survey 2	0	0	3	11	49
2iv	Survey 1	1	0	3	16	43
	Survey 2	0	1	2	14	46
2v	Survey 1	0	1	2	15	45
	Survey 2	0	1	3	12	47
3i	Survey 1	6	13	21	15	8
	Survey 2	12	15	17	10	9
3ii	Survey 1	30	15	13	5	0
	Survey 2	36	9	10	8	0
3iii	Survey 1	16	11	16	9	11
	Survey 2	16	11	17	9	10
3iv	Survey 1	27	14	12	7	3
	Survey 2	27	12	9	11	4
3v	Survey 1	28	22	8	2	3
	Survey 2	31	11	12	5	4
3vi	Survey 1	12	15	14	17	5
	Survey 2	20	6	12	19	6
4a	Survey 1	21	11	8	15	8
	Survey 2	8	6	12	13	24
4b	Survey 1	35	2	5	2	0
	Survey 2	36	8	5	4	1
5	Survey 1	0	3	11	19	30
	Survey 2	0	6	19	5	33
6	Survey 1	0	2	13	21	27
	Survey 2	3	5	16	16	23
7	Survey 1	0	0	4	12	47
	Survey 2	2	2	2	13	44
8	Survey 1	13	14	12	11	13
	Survey 2	7	20	7	12	17

Appendix e-3. Email sent to trial participants immediately prior to public results reveal

Dear Participant:

Thank you for participating in the CCSVI treatment trial. We are all very grateful for your contribution that has led to a more complete understanding of CCSVI and its effect on multiple sclerosis.

I am calling you because we have recently analyzed the results up to the end of the first year for all participants. The results of the study will be discussed at a major medical conference in the near future. This will most likely be reported by Canadian news networks. We wanted all the participants to be the first to hear these findings.

At this time we can only report to the overall results and not your individual results. The study enrolled 104 participants from across Canada, and all except one continued in the study throughout the first year of assessments.

The key questions the study was designed to address were safety and improvement in patient reported outcomes such as fatigue, brain fog, pain, before the cross over at week 48. While some participants did feel better, overall there was no difference between those that received the venoplasty initially and those that did not.

The next step is getting this information published in a medical journal. That process can take several months because it is reviewed by experts who may ask for additional details. We will keep you informed of further major developments by telephone, mail or email whichever is your preference.

Once again, on behalf of all of us, thank you

Appendix e-4. Email sent to trial participants immediately following public results reveal

Canadian CCSVI study update - Results announced Wednesday March 8th, 2017

Dear [Name]:

Thank you for participating in the CCSVI study. We had hoped that this could lead to a better understanding of how important symptoms of MS could be affected by blood flow from the brain.

By now you are aware that the study failed to show a benefit of venoplasty. At this point all of you have had the venoplasty, and would have formed your own views on the experience.

These results may come as a big disappointment. If it is causing you stress, please contact us at MS.NMO_Research@ubc.ca, ask questions and share your concerns. With a topic as important as CCSVI, information can become distorted through social media and we want to help work through this with you. Your concerns will be treated confidentially and with respect.

Addendum for participants who have not finished all study visits:

Your study visits will continue as planned. These are important for monitoring safety and assessing your MS status throughout the study. If you have any questions or concerns about the visit, please contact us.