

# Transition of Care to an Adult Spina Bifida Clinic: Patient Perspectives and Medical Outcomes

## Transition Survey: Patient version

We would like to start by asking a few general questions about you.

A. Demographics of the patient:

a. Did you do any school or training after you finished high school?

- i. Yes \_\_\_
- ii. No\_\_\_
- iii. I am in high school\_\_\_

If yes, did you/ do you: (choose all that apply to you)

- Go to University (e.g Dalhousie) \_\_\_
- Go to community college (e.g. NSCC) \_\_\_
- Do a job specific program (e.g. apprentice to be a mechanic) \_\_\_
- Other \_\_\_\_\_
- How many years was your program? \_\_\_\_\_

b. Do you have a job? Yes \_\_\_ No\_\_\_

If yes, what do you do? \_\_\_\_\_

c. Do you live

- i. By yourself \_
- ii. In an assisted care home (e.g. group home) \_
- iii. With your parents \_
- iv. With a partner \_
- v. With a roommate \_

d. Would you say your mobility is (or, I get from place to place)

- i. independent (on my own) \_
- ii. with an aid (e.g. crutches, walker) \_
- iii. with a wheelchair \_
- iv. other\_\_\_\_\_

e. Do you receive help with personal care? (e.g. bathing, catheterizing)

- i. No \_
- ii. Yes\_

Comments\_\_\_\_\_

\_\_\_\_\_

f. Do you have a family doctor

- i. Yes \_
- ii. No \_

Comments\_\_\_\_\_

\_\_\_\_\_

**B. We want to know about your experience going from the IWK spina bifida clinic (or other children’s spina bifida clinic or general adult urology clinic) to the adult spina bifida clinic at the QEII. Please tell us if you disagree, somewhat disagree, somewhat agree or agree with the comments below. You can refer to the card we sent in the mail with the letter about the study and your consent form. Please ask for an explanation if you do not understand a question.**

- 0 disagree
- 1 somewhat disagree
- 2 somewhat agree
- 3 agree

1. Did you go to the IWK spina bifida clinic up until the time that you started going to the QEII adult SB clinic?

- i. Yes \_\_\_\_\_
- ii. No \_\_\_\_\_

If no, where did you get your specialist care as a child or before you started going to the adult clinic?

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2. Some people find that as they change to adult care there are “bumps” or “problems” along the way or things they wish had gone better. The next questions will ask you about some of these. Please remember that it is OK if you say these weren’t a problem for you. Also, remember that we will not tell anyone at the IWK or QEII clinic what you tell us. Your answers are confidential (private). They are only to help us learn how to make the change (transfer) better for patients.

- a. My IWK doctors were unable to ‘let go’ of my care                    0        1        2        3
- b. My IWK nurses were unable to ‘let go’ of my care                    0        1        2        3
- c. Other caregivers (e.g. Occupational therapists or physiotherapists) at the IWK were unable to ‘let go’ of my care                    0        1        2        3
- d. I felt like the IWK doctor/nurses were glad to see me leave    0        1        2        3
  - i. If you agree or somewhat agree, Why did you feel this way?

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- e. My parents were unable to ‘give up’ control of my care            0        1        2        3
  - i. Why do you think this was the case?

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- f. My adult doctors don’t know very much about spina bifida    0        1        2        3

- g. Did you feel you could leave the IWK and start going to the adult clinic at a time and date that was good for you?                    0        1        2        3

- h. If you did not feel ready to start going to the adult clinic did the clinics allow you to put off changing until you were ready? Yes\_\_\_\_\_ No\_\_\_\_\_
- i. When I started going to the adult spina bifida clinic, I felt ready to start seeing an adult doctor and did not feel I needed to talk to a pediatrician any longer  
0 1 2 3
- j. The people at the IWK talked to me about changing my care to the adult clinic before I started going to the adult clinic  
0 1 2 3
- i. How long before you went to the adult clinic did the IWK people mention it to you? \_\_\_\_\_
- ii. Was this long enough? Yes\_\_\_\_\_ No\_\_\_\_\_
- iii. If no, how much time would have been good? \_\_\_\_\_
- k. I understood my spina bifida and how it affects me before I left the IWK clinic  
0 1 2 3
- i. If you disagree, what didn't you understand about your spina bifida?  
\_\_\_\_\_  
\_\_\_\_\_
- ii. What questions did you have about your spina bifida?  
\_\_\_\_\_  
\_\_\_\_\_
- l. My parent/caregiver helped me change to the adult clinic 0 1 2 3
- m. I felt like the IWK clinic and the adult clinic talked to each other about my care  
0 1 2 3
- n. The adult spina bifida clinic can answer my questions about money troubles if I have any  
0 1 2 3
- o. The adult spina bifida clinic can answer my questions about job troubles if I have any  
0 1 2 3
- p. I had the opportunity to go to the adult spina bifida clinic before leaving the IWK clinic  
0 1 2 3
- q. I wish I had had the chance to visit the adult spina bifida clinic before completely leaving the pediatric clinic  
0 1 2 3
- r. I helped make decisions (choices) about my transfer to the adult spina bifida clinic  
0 1 2 3
- s. I wish I could have made more decisions (choices) about going to the adult spina bifida clinic  
0 1 2 3
- i. What would you have liked to make decisions about?  
\_\_\_\_\_  
\_\_\_\_\_

C. Patient Satisfaction:

a. Overall, how happy were you with the care you received at the IWK clinic?

- 0 Worst experience ever
- 1
- 2
- 3
- 4
- 5 I was satisfied
- 6
- 7
- 8
- 9
- 10 Best experience ever

b. Overall, how happy are you with the care delivered at the adult clinic?

- 0 Worst experience ever
- 1
- 2
- 3
- 4
- 5 I am satisfied
- 6
- 7
- 8
- 9
- 10 Best experience ever

c. Did anything that happened during the transfer of your care to the adult clinic effect how happy you are with the adult spina bifida clinic? Yes\_\_\_\_\_ No\_\_\_\_  
If yes, what happened?

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d. In your opinion, how could the adult clinic be better for you?

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e. Is there anything that I didn't ask you about that you think was important about how you felt about you change to the adult SB clinic?

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You have now completed the last survey. Thank you for your time! We appreciate your participation in this study.