

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

Transition Survey: Parent/Caregiver Perspective

Please let us know how you are related to the person who was transferred to the adult spina bifida clinic. Are you the:

Parent _____

Primary Caregiver _____

Both _____

Other _____

Was the person you care for able to complete the 'patient version' of this survey? Y__ N__

A. Demographics of the patient:

a. Did they do any training after they finished high school?

i. Yes __

ii. No__

iii. They are still in high school__

If yes, did they or do they currently: (choose all that apply)

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 their program? _____

b. Do they have a job? Yes __ No__

If yes, what do they do? _____

c. Do they live

i. Alone _

ii. In an assisted care home (e.g. group home) _

iii. With you _

iv. With a partner _

v. With a roommate__

d. Would you say their mobility is (they get from place to place)

i. independent (on their own) _

ii. with an aid (e.g. crutches, walker) _

iii. with a wheelchair _

iv. other _____

e. To your knowledge, do they receive help with personal care? (e.g. bathing, catheterizing)

i. No _

ii. Yes_

Comments _____

f. Do they 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 the patient leave the IWK spina bifida clinic and start going to the QEII adult spina bifida clinic straight away?

Yes ___

No ___

If no, where did they get their specialist care as a child or before going to the QEII adult SB clinic?

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 or the patient. 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 and their caregivers.

a. The IWK doctors were unable to ‘let go’ of patient care 0 1 2 3

b. The IWK nurses were unable to ‘let go’ of patient care 0 1 2 3

c. Other caregivers (e.g. Occupational therapists/ Physiotherapists) at the IWK were unable to ‘let go’ of patient care

0 1 2 3

d. I felt like the IWK doctor/nurses were glad to see the patient leave

0 1 2 3

i. If you agree or somewhat agree, Why did you feel this way? _____

e. I felt, it was difficult to ‘give up’ control of care

0 1 2 3

i. Why did you feel this way? _____

f. The adult doctors don’t know very much about spina bifida

0 1 2 3

g. Did you feel your child/ the patient could leave the IWK and start going to the adult clinic at a time and date that was good for them?

0 1 2 3

h. If they did not feel ready to start going to the adult clinic did the clinic allow them to put off changing until you were ready? Yes_ No__

i. When they started going to the adult spina bifida clinic, I felt they were ready to start seeing an adult doctor and did not need to talk to a pediatrician any longer
0 1 2 3

j. The people at the IWK talked about changing care to the adult clinic before the patient started going to the adult clinic
0 1 2 3

i. How long before the patient went to the adult clinic did the IWK people mention it to them?

ii. Was this long enough? Yes_____ No_____

iii. If no, how much time would have been good? _____

k. The patient understood spina bifida and how it affects them before leaving the IWK clinic
0 1 2 3

l. I helped my child/the patient 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 patient care
0 1 2 3

n. The adult spina bifida clinic can answer the patient's questions about money troubles if they have any
0 1 2 3

o. The adult spina bifida clinic can answer the patient's questions about job troubles if they have any
0 1 2 3

p. The patient had the opportunity to go to the adult spina bifida clinic before leaving the IWK clinic
0 1 2 3

q. I wish the patient 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 the 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. Caregiver 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 SB clinic?

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

c. Overall, how happy do you think your child/ the patient was with the care they received at the IWK clinic?

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

d. Overall, how happy do you think your child/the patient is with the care delivered at the adult SB clinic?

- 1 Worst experience ever
- 1
- 2
- 3
- 4
- 5 they are satisfied

- 6
- 7
- 8
- 9
- 10 Best experience ever

e. Did anything that happened during the change of care to the adult clinic effect how happy you are, or your child/ the patient is, with the adult SB clinic? Yes_____ No_____
If yes, what happened?

f. In your opinion, how could the adult clinic be better for you and your child/the patient?

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