

CONSENT FORM

Title of Project:

HELP US UNDERSTAND THE NEEDS OF FAMILIES TO IMPROVE MEDICAL AND SURGICAL CARE

You are invited to participate in quality improvement project because you have a child receiving care at the at BC Children's Hospital.

Our project aims to understand the social background and needs of families of patients at at BC Children's Hospital. These findings will help us advocate for improved medical and surgical care.

Your participation is voluntary. If you decide to participate, you may withdraw at any time without any negative consequences to the medical care, education, or other services that you are entitled to or are presently receiving.

If you decide to participate, we will provide you with a paper questionnaire to complete a 20-minute survey. **You do not have to answer any question that you do not want to.**

Your survey responses will be added to your child's clinic visit record and reviewed for topics that you may want to discuss with your doctor or other health care provider. Your doctor may refer you to other professionals for assistance.

When you complete the survey, your responses will be directly recorded into a secure database stored in BC Children's Hospital Research Institute's Secured Network electronically for five years. Access to your survey responses will be limited to the principal investigators and your child's medical/surgical care team and the technical support team at BC Children's Hospital Research Institute.

Your confidentiality will be respected. Participants will not be identified by name in any reports of the completed study. Information that discloses your identity will not be released without your consent unless required by law. All records will be kept confidential.

Your personal information is subject to protections under the BC Freedom of Information and Protection of Privacy Act (FIPPA). The collection of your individually identifiable information is authorized by section 26 (c)(e) of FIPPA. The identifiable information collected through the survey will only be used for the purposes listed on this form.

If you have any questions about your information and this survey, or you would like to withdraw your consent, please contact either principal investigator:

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1. **Do you have a family doctor, nurse practitioner, counselor or other health provider?**
 - Yes
 - No

2. **If yes, can you turn to them for help with disability forms, nutrition/caloric supplements (eg. Vitamins/Boost), housing, transportation related forms, etc?**
 - Yes
 - No
 - Unsure

3. **Do you ever ask anyone to come along with you to your child's appointments and help?**
 - Yes
 - No

4. **Do you feel you have adequate social support, such as family, friends, or others for help or encouragement?**
 - Often
 - Sometimes
 - Rarely

5. **How important is it to you to have your health provider team (nurse, doctor, nurse practitioner) ask about financial or other social stresses in your life?**
 - Very Important
 - Somewhat Important
 - Neutral
 - Not important
 - Never an issue

6. **How easy is it for you to get an appointment to see a doctor or other health care provider about you, or your child's health?**
 - Very difficult
 - Difficult
 - Neutral
 - Easy
 - Very easy

7. **How important is it for you to be included by your health care providers in the decisions about your child's health?**
 - Very important
 - Somewhat important
 - Neutral
 - Not important
 - Not ever an issue

8. How important is it for you to be treated with respect by your health care team (eg. doctors, dentists, nurses, nurse practitioners, psychologists, medical social workers, therapists (physical, occupational, speech))?

- Very important
- Somewhat important
- Neutral
- Not important
- Not ever an issue

9. How important is it for you that the front desk/medical office assistant staff to get to know you, or about your family's situation?

- Very important
- Somewhat important
- Neutral
- Not important
- Not ever an issue

Your family's social and financial situation can have a big impact on your child's health and well-being. In order to improve health care for children at BC Children's Hospital, we would like to better understand your family's situation. The reason we ask about postal code, is that children at our clinic come from all over the province, and we want to know how representative our project sample is of the population of British Columbia. This information is confidential and for quality improvement study purposes only.

10. Family composition

- How many people live in your home? _____
- How many children (under 19 years old) live in your household? _____

11. What is your postal code? First 3 characters ONLY. _____

Access to healthy foods and safe housing may have an effect on a child's health and well-being. We are interested in knowing if families across the province have differences in their ability to access healthy foods and safe housing. If there is a difference, we hope to use this data to advocate for better access to these.

12. Do you feel you have access to nutritious foods such as fresh fruits, vegetables, meats/fish, and dairy to provide for your family (eg. as per the Canada Food Guide)?

- Always
- Usually
- Never

13. Do you have a secure and stable place to live?

- Yes
- No
- Sometimes

It is recognized that 1-in- 5 children in British Columbia is experiencing some form of poverty [BC Poverty Report Card 2016]. Financial strain can impact the care of children, including problems being able to access health care or to purchase medications. The purpose of these questions is to understand how many children and families using this clinic may be experiencing financial strain.

14. At the end of the month, do you have difficulty making ends meet? (eg. paying for food and monthly bills)

- Never
- Sometimes (eg. a few times per year)
- Always (eg. every month)

15. Have you completed and sent in your tax forms for this past tax year to be considered for benefits?

- Yes
- No
- Unsure

16. Does the cost of essential medications, devices (splints, wheelchair, etc.), disposables (catheters, diapers, etc.), or other medical supplies affect your ability to follow prescribed treatment plans?

- Yes (Please explain how this affects your child's treatment plan.)
 - No
-
-

17. Does your family receive any of the following? (Check All that Apply)

- Federal Child Tax Benefit
- Federal [Disability](#) Child Tax Benefits (T2201 Disability Tax Credit Certificate filled out by a **doctor or other special needs provider**)
- Persons with disabilities (PWD) assistance for the Province
- First Nations Health benefits
- Other payments for a disability (such as ICBC payments, Worker's Compensation, Long Term Disability etc.)
- Extra-Income supplements (eg. Income assistance, Employment Insurance (EI))
- Other: _____

18. Do you identify as any of the following? Please check all that apply.

- Indigenous/Aboriginal**
- First Nations (with or eligible for status)**
- Metis**
- Inuit**
- English as a Second (or Learned) Language (eg. ESL, ELL)**
- Immigrant**
- NEW Canadian (permanently relocated from another country in the past 5 years)**
- Refugee**
- Other:** _____
- None of the above**

19. Do you or anyone in your household identify as a minority: visually, ethnically or culturally?

- Yes
- No

20. Did you, your parents, your spouse, or your spouse's parents ever attend residential school?

- Yes
- No
- Prefer not to answer

21. If you answered "Yes" in question 20, please indicate who attended residential school.

- The child's mother
- The child's maternal grandmother
- The child's maternal grandfather
- The child's father
- The child's paternal grandmother
- The child's paternal grandfather
- Other (please specify): _____

Socioeconomic status (SES) can give researchers and health care providers important insight into a family's life. SES can, in general, be estimated as a combination of education, occupation and income.

22. What is your highest level of formal education?

- Some high school
- High school diploma or leaving certificate
- Apprenticeship or other trades certificate or diploma
- College, CEGEP or other non-university certificate or diploma
- University certificate or diploma below bachelor level
- University certificate or diploma (Bachelor's degree)
- Advanced degree (i.e. Masters, JD, MD, PhD)
- Other: _____

23. Do you work outside the home?

- Yes
- No

24. What is your estimated annual household income?

- \$0- \$20,000
- \$20,000 - \$40,000
- \$40,000 - \$60,000
- \$60,000 - \$80,000
- \$80,000 - \$100,000
- \$100,000-\$120,000
- \$120,000 and over+

Having supports in the family and community can help families overcome adversity and develop resilience. The following questions ask about the supports in your life.

25. In times of stress, how many people can you turn to for support (i.e. friends, partner, parents, grown children, neighbors, elders, spiritual/ religious guide, teacher, coach, health nurse, doctor, co-worker, etc)?

- Less than 4
- 4-8
- 9-13
- 14-19
- More than 20

26. Which of the following apply to you, including your childhood? Please check all that apply.

- When I was little, other people helped my parents take care of me and they seemed to love me.
- I've heard that when I was an infant, someone in my family enjoyed playing with me and I enjoyed it too.
- When I was a child, there were relatives in my family who helped me feel better when I was sad or worried.
- When I was a child, neighbors or my friends' parents seemed to like me.
- When I was a child, teachers, coaches, youth leaders or ministers were there to help me.
- Someone in my family cared about how I was doing in school.
- My family, friends and neighbors talked about making our lives better.
- We had rules in our house and were expected to keep them.
- When I felt really bad, I could almost always find someone I trusted to talk to.
- As a youth, people noticed that I was capable and could get things done.
- I was independent and a go-getter.
- I believe that life is what you make of it.
- There are people I can count on now in my life.
- There are other factors in my life that have or do make me resilient in the face of hardship
- What are some of these factors? _____
- I am having a hard time feeling resilient right now.
- None of the above.

27. What types of information do you think might assist you and your family on this health journey at our clinic?

Please check all that apply:

- Information on transportation
- Information on lodging / places to stay while at the hospital
- Parking information or assistance
- Information about other children with similar conditions
- Information on eligibility for disability supports for my child
- Information on assistance to cover the costs of essential medicines, devices or supplies
- Information about applying for First Nations' benefits
- Immigration or New Canadian Services
- Other: _____

I would prefer to receive any information from this hospital: online, print or both (Circle choice)

28. Is there anything your doctors or this clinic could do to make this visit easier on you and your family? Please explain. If you need more room, you may use the back page.

Adverse Childhood Experiences (ACEs) – *Optional*

The purpose of this section is to determine how many families receiving services at this clinic have had some of these experiences and how we might improve child health outcomes.

We recognize that the following questions are sensitive. If at any time you feel uncomfortable with these questions, you may choose not to continue.

What are Adverse Childhood Experiences (ACEs)?

Childhood experiences, both positive and negative, can have a tremendous impact on lifelong health and future opportunities. Much of the expert research in this area is referred to as Adverse Childhood Experiences (ACEs).

This second part of the questionnaire is something we also provide to each family. These ask some personal questions about longer term health risks associated with exposure to stress and ACEs. Our health care team believes that recognizing risks is an opportunity for us to address and help you prevent future health problems.

- ACEs have been shown to occur in all income levels, races, and cultures.
- About 2/3 of individuals report at least one ACE
- 4/10 have two or more
- 1/8 have four or more

Having four or more ACEs may increase a child's risk of having health problems as an adult.

For more information, you may wish to google "[ACEs Quiz NPR](#)": *Take the ACE Quiz – And Learn What It Does and Doesn't Mean*

Instructions

1. The questions on the following two pages are now recommended to be asked in Primary Care and by Pediatricians across North America in an effort to better understand and support families and prevent ongoing ACEs.
2. We will ask you to review the statements and ask you to [write down the number](#) of statements that apply to your child, [not which ones](#).
3. If you have any questions, would like to stop, or withdraw your consent from this part of questionnaire, please indicate this to our quality improvement research assistant and pick up your coffee card.

Adverse Childhood Experiences (ACEs) - *Optional*

Many children experience stressful life events that can affect their health and wellbeing. The results from this questionnaire will assist your child's doctor in assessing their health and determining guidance.

Please read the statements below. Please **DO NOT mark or indicate** which specific statements apply to your child.

Count the number of statements that apply to your child and write the total number in the box provided.

Of the following statements, **HOW MANY** of these "ACEs" apply to your child?

A. Of the statements below, how many apply to your child? Write the total number in the box.

At any point since your child was born...

- Your child's parents or guardians were separated or divorced.
- Your child lived with a household member who was depressed, mentally ill or attempted -suicide.
- Your child lived with a household member who served time in jail or prison.
- Your child saw or heard household members hurt or threaten to hurt each other.
- Your child lived with someone who had a problem with drinking or using other drugs.
- A household member swore at, insulted, humiliated, or put down your child in a way that scared your child OR a household member acted in a way that made your child afraid that s/he might be physically hurt.
- Someone touched your child's private parts or asked your child to touch their private parts in a sexual way.
- More than once, your child went without food, clothing, a place to live, or had no one to protect her/him.
- Someone pushed, grabbed, slapped or threw something at your child OR your child was hit so hard that your child was injured or had a bruise or a mark.
- Your child often felt unsupported, unloved and/or unprotected.

B. Of the statements below, how many apply to your child? Write the total number in the box.

At any point since your child was born...

- Your child was in foster care.
- Your child experiences harassment or bullying at school.
- Your child lived with a parent or guardian who died.
- Your child was separated from their primary care giver during deportation or immigration.
- Your child had a serious medical procedure or life-threatening illness.
- Your child often saw or heard violence in their neighbourhood.
- Your child was often treated badly because of race, sexual orientation, place of birth, disability, or beliefs.

If any of these questions concerned or distressed you, please request time to speak with your health providers here or your family doctor. Your doctors or team may refer you to other professionals for assistance.

Would you like to speak to someone today?

- Yes
- No

Would you like more resources on Adverse Childhood Experiences and Resiliency?

- Yes
- No

We would appreciate your feedback to make this questionnaire better for all families. If you have any suggestions or further questions, please contact us.

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