What Else Matters? The BEARS Survey

Information and Consent Form

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

Our project aims to better understand the needs of families of patients at BC Children's Hospital, and what matters to you.

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.

We recognize that some of the questions are sensitive. If at any time you feel uncomfortable with these questions, you can skip them or choose not to continue.

We would appreciate your feedback on this questionnaire. Your comments at the end will help guide us to provide better care for families in the future.

A copy of your survey response will be added to your child's clinic visit record so that our team may be more informed and responsive to your care. Your doctor or nurse may also help refer you to other professionals for assistance.

When you complete the survey, your responses will be 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 pediatric 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 project. 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.

BEARS:

Barriers to care

Economic Factors

Adversity

Resiliency

Social Capital

Thank you for completing the survey.

If you have any questions about your information and this survey, or you would like to withdraw your consent, please contact us.

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For extra information and resources, please scan the QR code below or follow the link.

http://www.opsei.bc.ca/SurgeryAndSociety.html

BARRIERS TO CARE

1| If you have a family doctor, nurse practitioner, counselor, or other general health provider, can you turn to them for support for help with disability forms, nutrition/caloric supplements (e.g. Vitamins/Boost), housing, transportation related forms, etc.?

- ☐ Yes
- ☐ No
- ☐ I don't have a regular health provider

2| How important is it that your health care provider include you in the decisions about your child's health?

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

3| Is it important for you to have a system to track your child's appointments and/or other health needs?

- ☐ Yes
- ☐ No
- ☐ Not an issue or we don't need this

4| If you have a system, please explain. If you don't, describe what would help. You may use space on the last page.

_____

_____

ECONOMIC FACTORS & FAMILY SUPPORTS

1| Do you submit tax forms each year to be considered for your child or disability eligibility?

- ☐ Yes
- ☐ No
- ☐ Unsure

2| At the end of the month, do you have difficulty making ends meet?

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

3| Does the cost of essential medications, devices, disposables, or other medical supplies affect your ability to follow prescribed treatment plans, or provide care for your child?

- ☐ Yes
- ☐ No
- If yes, how? _____

4| How many people live in your home? _____

5| How many children (under 19 years old) live in your household? _____

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

7| What is your estimated annual household income?

- $0 - $40,000
- $40,000 - $80,000
- $80,000 - $120,000
- $120,000 and over

ADVERSITY

1| Have you ever felt excluded or uncomfortable during your child's healthcare journey because of extra needs, language, culture, gender, or other reasons?

- Yes
- No
- Unsure

If yes, please explain. You may also use space on the last page.

_____

_____

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

- Yes
- No

3| Have you ever received extended benefits, child welfare, or other social services for your child or for their health needs?

- Yes
- No
- Unsure

If yes, check all that apply:

- Federal Disability Child Tax Benefits (**T2201 Disability Tax Credit Certificate filled out doctor or other provider)**
- Extra-Income supplements (e.g. Income assistance, Employment Insurance (EI))
- Foster Care or Family Preservation Worker
- Child and Youth with Special Needs (CYSN)
- Child and Youth Mental Health (CYMH)
- First Nations, Metis, Inuit, or other Indigenous Health Benefits
- Other: _____

RESILIENCY & SOCIAL CAPITAL

1| Which of the following apply to you (parent/guardian).

- When I was a child, family members, teachers, coaches, youth leaders, or others were there to help me
- There are people I can count on now in my life
- I am having a hard time feeling resilient right now

2| Do you feel there is a supportive network available to help you or your family members in times of need, if needed, at this hospital or nearby? (e.g. spiritual care, quiet spaces, healing circle, social work support, patient navigators, interpreters, etc.)

- Often
- Sometimes
- Rarely

3| What is your relationship with your child?

- ☐ Mother
- ☐ Father
- ☐ Grandparent
- ☐ Other family member (sister, aunt, uncle, etc.)
- ☐ Foster Parent
- ☐ Social Worker
- ☐ Other: _____

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

- ☐ Fewer than 4
- ☐ 4-8
- ☐ 9-13
- ☐ 14-19
- ☐ More than 20

Optional – ACEs

What are Adverse Childhood Experiences (ACEs)?

Childhood experiences, both positive and negative, can impact lifelong health and future opportunities. Much of the expert research in this area is referred to as Adverse Childhood Experiences (ACEs). Many children experience stressful life events that can affect their health and wellbeing. The results from this questionnaire will assist your child's health care team in assessing health and determining guidance.

This part of the questionnaire asks 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.

Please read the following statements. Please <u>DO NOT</u> mark or indicate which specific statements apply to your child. We recognize that the following questions are sensitive. <u>This section is optional</u>. You can also <u>choose not to continue</u>.

Count the number of statements that apply to your child and <u>write the total number in the box</u> provided:

☐ (TOTAL ONLY)

At any point since your child was born…
-You 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 was in foster care.
-Your child had a serious medical procedure or life-threatening illness.
-Your child often saw or heard violence in their neighborhood.
-Your child was often treated badly because of race, sexual orientation, place of birth, disability, or beliefs.

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

	(TOTAL ONLY)

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.

-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 him/her.

-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 mark.

-Your child often felt unsupported, unloved, and/or unprotected.

Extra Space for Responding to Earlier Questions:

Is there anything your doctors or this clinic could do to support you or to make your visits easier on you and your family? Do you have any suggestions to improve this survey? You may also write directly on the questions.