

Parental Comfort, Preferences, and Factors Influencing Decisions to Consent to Child Participation in Research in the Emergency Department

For each question, please select the option that is closest to how you feel.

1. I would be comfortable being approached by a university student trained for identifying and approaching families in the emergency department for a discussion of research that my child is eligible for.

1	2	3	4
Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree

2. I would be comfortable being approached by a research nurse trained for identifying and approaching families in the emergency department for a discussion of research that my child is eligible for.

1	2	3	4
Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree

3. I would be comfortable with research staff approaching me about research my child is eligible for when I first arrive in the emergency department before my child is seen by the triage nurse (the nurse who prioritizes patients arriving at the emergency department).

1	2	3	4
Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree

4. I would be comfortable with research staff approaching me about research my child is eligible for after being seen by the triage nurse (the nurse who prioritizes patients arriving at the emergency department) while waiting for a physician to see my child.

1	2	3	4
Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree

5. I would be comfortable with research staff approaching me about research my child is eligible for after my child has been seen by a physician.

1	2	3	4
Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree

6. I would be comfortable discussing research that my child is eligible for in the main waiting room.

1	2	3	4
Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree

- 7.** I would be comfortable discussing research that my child is eligible for in a separate area of the main waiting room.

1	2	3	4
Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree

- 8.** I would be comfortable discussing research that my child is eligible for In an exam room.

1	2	3	4
Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree

- 9.** I would be comfortable being given a detailed description of the research my child is eligible for by watching a video recording of a study investigator explaining the research study.

1	2	3	4
Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree

- 10.** I would be comfortable being given a detailed description of the research my child is eligible for from a research nurse (emergency department nurse who works with the research team) who verbally explains all of the details.

1	2	3	4
Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree

- 11.** If my child was a participant in a research project that requires follow-up, I would be comfortable being followed up with a scheduled visit from research personnel to my home.

Yes No

- a. If yes, how many times would you be comfortable being followed up with a scheduled visit from research personnel to your home (select one):

- i. 1 or 2 times
- ii. 3 to 5 times
- iii. Greater than 5 times

- b. How long of a time period would you be comfortable being followed up with a scheduled visit from research personnel to your home (select one):

- i. 1 week or less
- ii. greater than 1 week but less than 1 month

- iii. greater than 1 month but less than 3 months
- iv. greater than 3 months but less than 6 months

12. If my child was a participant in a research project that requires follow-up, I would be comfortable being followed up with a scheduled phone call from research personnel to my home.

Yes No

- a. If yes, how many times would you be comfortable being followed up with a scheduled phone call from research personnel (select one):
 - i. none
 - ii. 1 or 2 times
 - iii. 3 to 5 times
 - iv. Greater than 5 times
- b. How long of a time period would you be comfortable being followed up with a scheduled phone call from research personnel (select one):
 - i. 1 week or less
 - ii. greater than 1 week but less than 1 month
 - iii. greater than 1 month but less than 3 months
 - iv. greater than 3 months but less than 6 months

13. If my child was a participant in a research project that requires follow-up, I would be comfortable being followed up with a scheduled visit to the hospital or emergency department.

Yes No

- a. If yes, how many times would you be comfortable being followed up with a scheduled visit to the hospital or emergency department (select one):
 - i. none
 - ii. 1 or 2 times
 - iii. 3 to 5 times
 - iv. Greater than 5 times
- b. How long of a time period would you be comfortable being followed up with a scheduled visit to the hospital or emergency department (select one):
 - i. 1 week or less

- ii. greater than 1 week but less than 1 month
- iii. greater than 1 month but less than 3 months
- iv. greater than 3 months but less than 6 months

14. If my child was a participant in a research project that requires follow-up, I would be comfortable being followed up via email.

Yes No

a. How many times would you be comfortable being followed up via email (select one):

- i. none
- ii. 1 or 2 times
- iii. 3 to 5 times
- iv. Greater than 5 times

b. How long of a time period would you be comfortable being followed up via email (select one):

- i. 1 week or less
- ii. greater than 1 week but less than 1 month
- iii. greater than 1 month but less than 3 months
- iv. greater than 3 months but less than 6 months

15. If my child is a participant in a research project that requires daily record keeping I would be comfortable keeping track with hard copy materials like a written diary or magnetic calendars and stickers.

1	2	3	4
Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree

16. If my child is a participant in a research project that requires daily record keeping I would be comfortable keeping track with internet based materials.

1	2	3	4
Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree

17. If my child is a participant in a research project that requires daily record keeping I would be comfortable keeping track by having research personnel call me.

1 2 3 4
Strongly Disagree Somewhat Disagree Somewhat Agree Strongly Agree

18. If further information becomes available about a treatment that was a part of a study my child was a participant in, I would be comfortable being contacted more than 1 year after our participation was complete

1 2 3 4
Strongly Disagree Somewhat Disagree Somewhat Agree Strongly Agree

19. I would consent for my child to participate in research if:

- a. it would help me learn more about my child's disease
 Yes No I Decline to Answer I Don't know
- b. my child's illness / disease is serious
 Yes No I Decline to Answer I Don't know
- c. it would help to increase medical knowledge
 Yes No I Decline to Answer I Don't know
- d. it would give us access to the newest drugs and/or best possible treatments
 Yes No I Decline to Answer I Don't know
- e. more visits will mean better care for my child
 Yes No I Decline to Answer I Don't know
- f. my child will receive more attention if he/she is in a study
 Yes No I Decline to Answer I Don't know
- g. the relationship with the emergency department staff (nurses and doctors) is important to me
 Yes No I Decline to Answer I Don't know

- h. it would possibly benefit other children
 Yes No I Decline to Answer I Don't know
- i. there is minimal risk to my child
 Yes No I Decline to Answer I Don't know
- j. the research team member who approached me was reassuring
 Yes No I Decline to Answer I Don't know
- k. the involvement of the paediatrician is important to me
 Yes No I Decline to Answer I Don't know
- l. my family/friends would want me to
 Yes No I Decline to Answer I Don't know
- m. I would like the free study materials
 Yes No I Decline to Answer I Don't know
- n. the financial benefit is appealing
 Yes No I Decline to Answer I Don't know
- o. I would like to be associated with the research study
 Yes No I Decline to Answer I Don't know
- p. other reasons:

(Please specify): _____

20. I would not consent for my child to participate in research because:

- a. I do not want my child in a 'study'
 Yes No I Decline to Answer I Don't know
- b. I am concerned about procedures (blood work for example)
 Yes No I Decline to Answer I Don't know
- c. I am worried about possible complications or side effects

Yes No I Decline to Answer I Don't know

d. I am too busy

Yes No I Decline to Answer I Don't know

e. I am concerned about the number of follow ups

Yes No I Decline to Answer I Don't know

f. I do not believe my child's illness / disease is serious

Yes No I Decline to Answer I Don't know

g. I do not agree with research due to religious reasons

Yes No I Decline to Answer I Don't know

h. I do not agree with research due to philosophical reasons

Yes No I Decline to Answer I Don't know

i. other members of my family would not want me to allow my child to participate

Yes No I Decline to Answer I Don't know

j. the study seems too complicated

Yes No I Decline to Answer I Don't know

k. other reasons:

(Please specify): _____

21. Have you ever consented to research that involved your child's participation?

(Select one): Y N

I Decline to Answer I Don't Know

22. Have you ever consented to be a participant in research?

(Select one): Y N

I Decline to Answer I Don't Know

23. Have you ever declined consent for your child's participation in a research project?

(Select one): Y N

I Decline to Answer I Don't Know

24. Have you ever declined consent for your participation in a research project?

(Select one): Y N

I Decline to Answer I Don't Know

Parent and Child Demographics:

1. Parent or guardian date of birth (day/month/year): ___ / ___ / _____

2. Child date of birth (day/month/year): ___ / ___ / _____

3. Parent or guardian gender: Male Female

4. Gender of child: Male Female

5. Relationship to child in the emergency department: Mother Father

Legal Guardian Other (specify):

6. Ethnicity (select one): Caucasian Black Asian First Nations/Aboriginal
 Other (specify): _____

I Decline to Answer I Don't Know

7. Citizenship (select one): Canadian Citizen by Birth

Canadian Citizen by Naturalization

Landed Immigrant in Canada

Visitor to Canada (including work or student VISA)

Other (Specify): _____

I Decline to Answer I Don't Know

a. If naturalized citizen or landed immigrant, how many years in Canada:

less than 1 year

Greater than 1 year but less than 5 years

Greater than 5 years

8. Household Income (select one): <\$10,000 >\$10,000 to <\$40,000

>\$40,000 to <\$80,000 >\$80,000 to <\$130,000 >\$130,000

Other (specify): _____

I Decline to Answer I Don't Know

9. Highest education completed (select one): Grade school High School

Some College College Graduate/Professional Vocational

Other (specify): _____

I Decline to Answer I Don't Know

10. Marital Status (select one): Single Married Divorced

Other (specify): _____

I Decline to Answer I Don't Know

11. How much access to internet do you have? (select one):

none

1 to 6 hours a day 7 to 12 hours a day

13 to 18 hours a day 19 to 24 hours a day

Other (specify): _____

I Decline to Answer I Don't Know

12. Primary (or usual) health care provider for child visiting emergency department today (select one):

Emergency Department Walk-in Clinic Family Doctor

Paediatrician Other (specify): _____

I Decline to Answer I Don't Know