



## Participant Information and Consent Form For permission to be contacted for future research at Specialized Services for Children and Youth (SSCY)

### Introduction:

**You are being asked for permission to be contacted in the future for participation in research studies at SSCY Centre.**

SSCY Centre houses a number of partners (including the Rehabilitation Centre for Children, Manitoba Possible, Child Development Clinic and Manitoba FASD Centre) that conduct research in child and youth disability to improve care received, increase community participation, enhance quality of life and learn more about issues that are important to children, youth and families. Research studies are designed to lead to better treatment and improve patient care.

We want to know if you may wish to participate in any of the studies that may be appropriate for you. By signing this form, you will allow research staff to contact you in the future to ask if you want to participate in any studies that are currently available. You have no obligation to participate in any study. If you decide not to participate your services at the Rehabilitation Centre for Children will not be affected.

### Procedures:

By signing this form, you are **only agreeing to be contacted to consider participation in future studies. You are not agreeing to participate in any study at this time.** If you are found to be eligible for a specific study, you will be contacted and provided with information on the new study. If you agree to participate you will need to sign a consent form for that study, at that time. It is always up to you to decide if you want to participate in a study that you get information about.

If you agree to be contacted, this will be documented as a check box in your child's electronic medical file. This information will help us determine if you are appropriate for specific studies. Consent to contact for research will be stored on the secure electronic medical records software (ACCURO) and a paper copy will be maintained by the research department at the Rehabilitation Centre for Children.

### Confidentiality:

Confidentiality of your information will be maintained in the following manner:

- The consent to contact check box will be stored on the secure Electronic Medical Records software (ACCURO) used to store medical records at the Rehabilitation Centre for Children.
- The signed consent form will be stored in a locked room at the Rehabilitation Centre for Children.
- Only the research staff at RCC will identify potential participants to email or mail out the information on behalf of the researcher beginning a new study.

- If the researcher wishes to phone potential participants to speak with you directly about a project, they will only have access to your name and phone number to phone you from SSCY Centre. Your personal information (name and phone number) can only be accessed on the secure research drive by the research staff and will not leave RCC/SSCY.
- ACCURO stores medical information for all clients at RCC. Our intent is to have an ongoing list of potential participants that may be interested in research. Information will be held in compliance of applicable provincial and federal privacy laws.

### **Quality Assurance:**

This consent form and the electronic check box may be inspected by a University of Manitoba Research Ethics Board and the Rehabilitation Centre for Children to ensure that your information is being collected and maintained in an ethical manner.

### **Voluntary Participation and Withdrawal:**

Your decision to participate in consent to contact for research is **completely voluntary**. While there may be no benefit to you, your participation will help researchers to quickly identify individuals who may be suitable for a particular research study. **If you change your mind after agreeing to this, your information can be removed from the database.**

The care you receive at the Rehabilitation Centre for Children will not be affected in any way if you decide not to agree to this future contact, or if change your mind and ask that your information be removed from the database.

### **Questions:**

If you have any questions about this database, or want to be added/removed please contact: Elizabeth Hammond, Research Associate, Rehabilitation Centre for Children at [ehammond@rccinc.ca](mailto:ehammond@rccinc.ca) Phone: (204)451-5702

If you have questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.



May we contact you in the future? Yes  No

Do you give permission to approved Rehabilitation Centre for Children research staff to review your electronic medical records, if applicable, for any future research studies?

Yes  No

***Review of records is done to confirm suitability to participate in future studies and will not be used for any other purpose.***

## **Statement of Consent**

### **I have read this consent form.**

- I have been given a copy of this form for my records.
- I have had the opportunity to ask questions and discuss what is involved.
- I understand that my personal information will be kept confidential.
- By signing this consent form, I have not waived any of my legal rights.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all your questions.

Child's printed name \_\_\_\_\_

Parent/legal guardian's printed name \_\_\_\_\_

Parent/legal guardian's signature \_\_\_\_\_ Date \_\_\_\_\_

Childs Date of Birth (day/month/year) \_\_\_\_\_

Email address \_\_\_\_\_

Phone Number \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

Postal code \_\_\_\_\_

Clinician's name (if gathering verbal consent) \_\_\_\_\_