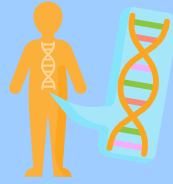


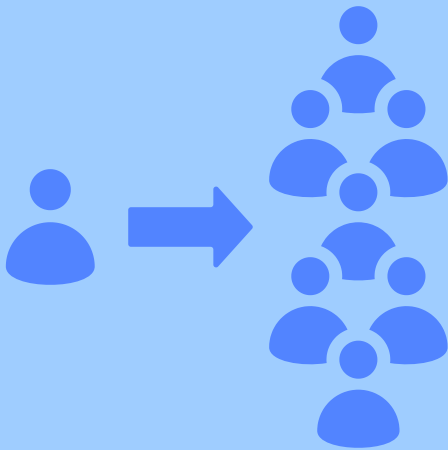
# RESEARCH READY



ID: Research Ready logo in a black square with Big R & little r.

## Mapping Your Parental/Participant Involvement in Genetic Research Engagement

It can be difficult to know where to begin when you're interested in being involved in research. One of the challenges is matching researchers with people with lived experience.



Research Ready is a tool for you to share a bit more about you and what type of research you may be interested in being part of. It is designed to match parents or people with lived experience with researchers who share similar interests. There are many ways to be involved in research. Research Ready allows you to share your health journey, experience, and skills. It is a prompt to think about what type of research matters to you and in what capacity you'd like to commit.

***Your opinion counts.***





# Research Ready- Mapping Your Parental/Participant Involvement in Genetic Research Engagement

Research Ready offers a snapshot of your lived experiences, skills, and availability for research engagement. It outlines personal experiences, expertise, and schedules, providing an overview crucial for understanding your background and potential contribution to research endeavors.

Full Name \_\_\_\_\_ Date \_\_\_\_\_  
Address \_\_\_\_\_ Contact Phone \_\_\_\_\_  
Email Address \_\_\_\_\_ Gender \_\_\_\_\_  
Aboriginal or Torres Strait Islander \_\_\_\_\_ Preferred mode of contact (Circle) :  
Country of Birth \_\_\_\_\_ Email / Phone / Text  
Do you speak another language at home? \_\_\_\_\_

## My Story

Please tell us about your story, your family. E.g., Do you and/or your child have a genetic condition?



## Have you or a family member been treated for any of the following health condition/s? (Please Tick)

- |   |  |  |
|---|--|--|
| <input type="checkbox"/> Food allergy         | <input type="checkbox"/> Chronic pain          | <input type="checkbox"/> Asthma          |
| <input type="checkbox"/> Eczema or psoriasis  | <input type="checkbox"/> Epilepsy              | <input type="checkbox"/> Type 1 Diabetes |
| <input type="checkbox"/> Hayfever             | <input type="checkbox"/> Motor Neurone Disease | <input type="checkbox"/> Type 2 Diabetes |
| <input type="checkbox"/> Multiple Sclerosis   | <input type="checkbox"/> Migraines             | <input type="checkbox"/> Other           |
| <input type="checkbox"/> Rheumatoid Arthritis |  |  |

## I have experience as a patient or carer with (tick all that apply):

- |  |   |   |
|--|---|---|
| <input type="checkbox"/> Public Hospitals      | <input type="checkbox"/> NDIS                 | <input type="checkbox"/> General Practitioner |
| <input type="checkbox"/> Private Hospitals     | <input type="checkbox"/> Occupational Therapy | <input type="checkbox"/> Paediatrician        |
| <input type="checkbox"/> Private Specialist(s) | <input type="checkbox"/> Physiotherapy        | <input type="checkbox"/> Neurologist          |
| <input type="checkbox"/> Community Health      | <input type="checkbox"/> Exercise Physiology  | <input type="checkbox"/> Geneticist           |
| <input type="checkbox"/> Other: _____          |   |   |

# My Research Profile

Please tell us about your research experience and interests.

Have you participated in research before?

Yes

No

If yes, please specify \_\_\_\_\_

## My Areas of Expertise (Personal & Professional)

Lived Experience

Advertising & Marketing

Law

Retail

Health care

Teaching

Research

Other: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

## What is my availability?

Quarterly

Monthly

Fortnightly

Weekly

Once Off

Less than 6 months

Less than 1 year

More than 1 year

Depends at the time

Infrequently

## How much time can I commit?

## Why I Want To Be Involved in Research

Please share why you are interested in being involved in research:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## What type of research matters to you? (Tick all that apply):

Prevention

Diagnosis

Treatment

Translation into clinical practice

Childhood disability

Dietary/Supplemental benefits

New treatments

Gene therapy

Digital Health

Other: \_\_\_\_\_

\_\_\_\_\_

## How I want to be involved in research

There are many ways that you can be involved in research. Please select the options that interest you below.

### Before the study

- Helping to develop ideas
- Planning outcomes and outcome measures that reflect lived experience
- Help develop scripts and communication materials for participants
- Planning how to recruit participants
- Contribute to funding applications
- Review documents and applications

### During the study

- Use my networks to advertise the study
- Participate in data collection (e.g., read study questions to participants, conduct interviews)
- Collect feedback
- Helping to interpret study results
- Place results in real-world context

### After the study

- Communicating findings, e.g., in written formats, presentations
- Develop public-friendly versions of results

If you have other ideas, please list them below:

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## What can you do to support me?

- Compensation (e.g., financial)
- Additional Briefs/Meetings
- Provide written information before meetings (e.g., agendas, slides)
- Flexibility in meeting times to accommodate my schedule
- Hybrid or audio-only meetings
- Closed captions
- Interpreter
- Large text format
- Other:

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This resource was created as part of the McMaster University, CanChild, and Kids Brain Health Network Family Engagement in Research Course in partnership with Healthy Trajectories: A child and youth disability research hub for those on the Melbourne Children's Campus. Copyright ©2023 Taylor Jenkin, Courtney Munro, Maya Pinn, Gehan Roberts. All rights reserved