ASPIRE Research Participant Registry User Manual

Mount Royal University

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About the Registry

The ASPIRE Research Participant Registry was created to provide researchers with a readily accessible population of parents who are interested in having their children participate in research. By doing this, we hope to make child-related research a more achievable task for researchers at Mount Royal University.

Registry Team Information

Joanne Park, PhD, R. Psych.

Dr. Joanne Park is an assistant professor at Mount Royal University and a registered psychologist with over 10 years of experience working with children and families in both research and clinical settings. During her graduate studies, Dr. Park actively maintained the participant registry for the Parenting Lab. This experience provided her with valuable expertise in implementing, building, and maintaining research registries, ensuring their effective use for participant recruitment and data management.

Contact: jlpark@mtroyal.ca

Michele Wellsby, PhD

Dr. Michele Wellsby is an assistant professor at Mount Royal University with experience working with children and families in research and community settings. During her graduate studies, Dr. Wellsby used the University of Calgary ChILD Research participant registry to recruit participants and train team members on using the registry. Dr. Wellsby also has experience building a client-management database at a local non-profit organization.

Contact: mwellsby@mtroyal.ca

Cass Foursha-Stevenson, PhD

Dr. Cass Foursha-Stevenson is an associate professor at Mount Royal University. Dr. Foursha-Stevenson assisted in the recruitment, maintenance, training, and implementation of the participant registry at the Rutgers University Infant Cognition Center. Additionally, she has research experience involving young children over multiple decades, creating relationships and collaborating with various local institutions, including daycares and preschools, in the recruitment of participants for her studies. Additionally, her lab is active in recruiting through online sources.

Contact: cfourshastevenson@mtroyal.ca

Contact Information

Email: childparticipantregistry@mtroyal.ca

Website:
https://www.mtroyal.ca/ProgramsCourses/FacultiesSchoolsCentres/Arts/Departments/Psychology/ResearchParticipationRegistry/index.htm

Facebook Page: https://www.facebook.com/profile.php?id=61577521163622

Technology/Software

Qualtrics
The Qualtrics servers are protected by Web Application Firewalls and an Intrusion Detection System (IDS) to monitor system access for unauthorized uses. All communications to and from the Qualtrics servers are encrypted using Transport Layer Security.

Google Forms
Google Forms is hosted on Google's secure servers. Information submitted through Google Forms is transmitted using encrypted connections (Transport Layer Security, TLS) and stored on Google infrastructure with safeguards designed to prevent unauthorized access. Google maintains security practices to protect data during transmission and storage.

Google Drive/Google Sheets
Google apps use various encryption technologies to ensure data safety, including HTTPS and Transport Layer Security.

Applying For Registry Access

Please read this document thoroughly and ensure you understand the registry usage guidelines.

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Check if your study is eligible for use of the database. Our registry may not be of use to you if any of the following statements do not apply:

- ➔ I am conducting research that is affiliated with MRU and will be regulated under MRU's HREB.
- ➔ I am a faculty member or a student conducting research under the supervision of a faculty member.
- ➔ I am conducting research that includes participants between the ages of 0-14.

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Fill out our Registry Access Request Form for your research. If you are a student researcher, you must be conducting research under the supervision of an MRU faculty member, who will be responsible for submitting this form. Be specific about the inclusion/exclusion criteria for your study and stay consistent with the information you include in your HREB application. At this point, you will likely not have HREB ethics approval, so leave the HREB file # field blank. Additionally, please read the researcher conduct and study checklist in the form to ensure you understand the expectations of using the ASPIRE Research Participant Registry. Once you submit the form, you will receive an email with your form response and an edit link. Please keep this email, as the edit link will need to be used later on.

Participant trust and retention are of utmost importance to the registry. For this reason, we ask that your registry request form include attachments to recruitment letters or invitations. This ensures that participants are only contacted for research that aligns with the interests of the registry.

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Once you have obtained ethics approval, use the edit link to the request form to update your information, including the HREB file # for your study. You will then be granted access to a Google Sheet including contact, age, and name information for people who meet the inclusion/exclusion criteria for your study.

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Request extended use of the registry. Once a year, we will contact you to request confirmation that you are still collecting data for your study. If you intend to continue recruiting through our registry, you will need to provide confirmation that ethics approval has been extended for your research.

Contacting Participants

Ensure that you are complying with the approved/preferred method of contact for everyone you reach out to. You may find this information by checking the "preferred method of contact" column in your list of participants on the Google Sheets file.

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Check for the last date that participants were contacted. Before contacting a participant, open the "Contact/Participation Log", search (Ctrl+F) for the participant's ID#, and check that the participant has not already been contacted in the last 2 weeks or already participated in a study in the last 3 months. The cells in the Google Sheet will be highlighted red if it is too soon to recruit them again (instructions below on using the "Contact/Participation Log"). This ensures that participants are not overwhelmed by research recruitment messages.

If you are contacting multiple families at once, you can check contact eligibility for your entire contact list in one step. In the "Contact/Participation Log", click into the "Search Tool" page at the bottom and paste your list of Participant IDs into the first column. The spreadsheet will automatically show which families are eligible to be contacted and when others may be contacted again. Make note of the families you are allowed to contact, and then delete the list of Participant IDs you pasted in.

When you have contacted a family or had them participate in your study, you will need to immediately update the "Contact/Participation Log" with that activity (instructions below).

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Contact the participants. The participants whom you will be able to contact have consented to be *contacted* for future research. Please keep this in mind when reaching out and kindly invite them to participate.

Each time you contact a participant to recruit for your study, please include the following instructions on removing themselves from the Child and Family Registry:

You are being contacted to be invited to participate in research because you signed up to be a part of the ASPIRE Research Participant Registry at Mount Royal University. We appreciate your ongoing involvement in research at our institution. If circumstances change and you would like to be removed from the registry, please contact us at childparticipantregistry@mtroyal.ca. Thank you!

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Update the "Contact/Participation Log" each time you contact a participant with the date you contacted them and any other additional notes that are relevant to the participant's ongoing involvement with the registry (e.g., a participant tells you about a range of dates they would like not to be contacted). Do the same when someone participates in your study. Both of these tasks can be completed by clicking into the "Update Tool" page at the bottom, pasting in all of the relevant Participant IDs, filling in your PI#, date contacted/participated, and whether participants were contacted for/participated in your study. Click the "Registry Tools" tab at the top of the page and select "Apply batch update (Update Tool)". Double-check the information you entered and click "OK".

Additional Note: To contribute to maintaining the registry for the use of future researchers at MRU, we ask that you share a brochure about the registry with participants you have recruited through other means. A brochure will be sent to you when you are given registry access approval.

Requesting Additional Data

You may find yourself still needing more data after a period of data collection. Every 4 months, you can request another database search based on your inclusion/exclusion criteria to determine if more participants who qualify for your research have signed up for the registry.

To do this, please contact us through our registry email to let us know you are requesting another database search. Any additional participant contact information will be uploaded to the existing Google Sheet.

Removing Data From Your Records

In some circumstances, participants may reach out to our registry staff requesting to be removed from the registry. If you are one of the researchers who have been granted access to that participant's information, we will contact you by email to ask you to remove that information from your records. Additionally, if a participant tells you that they would like to be removed from the registry database, please inform us as soon as possible or direct them to email us.

Responsible Handling of Data

The storage of participant data received from our registry should follow approved storage methods outlined in the approved HREB application for your study. Please be diligent in safeguarding participant information.

Ensure that in the consent form for your study, you have outlined how long participant information will be retained. Additionally, ensure participants understand the moment that the withdrawal of participation or data from your study will no longer be possible.

Frequently Asked Questions

Who can access the registry?
MRU researchers who have obtained ethics approval from the HREB and have submitted a Registry Access Request Form will gain access to a filtered subset of information from our database.

Can I use the registry to recruit for studies that are not affiliated with MRU?
No, the registry is strictly for research conducted at Mount Royal University.

Can I use the registry to recruit children from specific demographic backgrounds (e.g., bilingual families, neurodivergent children)?
Yes, however, this information is only used in filtering contact information for researchers. We do not share this information, so researchers will have to collect this data in their study processes.

Are there any restrictions on the types of research studies that can use the registry for recruitment?
Researchers hoping to recruit using our registry should be conducting research on children and family topics. When request access forms are reviewed, our team will screen for studies that meet this criteria.

How long does it take to receive approval after submitting a Registry Access Request Form?
Roughly 2 weeks.

What happens if my study's inclusion/exclusion criteria change after I've already been granted access?
In this case, please use the edit link to your completed Registry Access Request Form in Google Forms. Include your original criteria and the new criteria, and resubmit the form. Please attach your HREB modification approval as well.

Can multiple researchers on my team access the registry data, or is access limited to the principal investigator?
Only the principal investigator will be given account access to the Google Sheet.

Can I recruit participants for multiple studies at the same time if they meet the criteria for more than one?
The use of participant information from our registry is restricted to approved studies. You may submit for access approval for a second study following the same protocol.
My study entails participation that lasts for longer than one day. How can I update the "Contact/Participation Log" to reflect this?
If a participant has consented to participate, record the anticipated final date of participation instead.

What should I do if I suspect a data breach or accidental exposure of registry participant information?
Please email us as soon as possible if you are made aware of a breach in data protection.

Can I request updates to the registry's participant information (e.g., contact details, child's age) if I suspect they are outdated?
Yes, you may suggest information changes via comments in the researcher notes column of the Google Sheet specific to your study (titled with your PI#) that you have been granted access to.