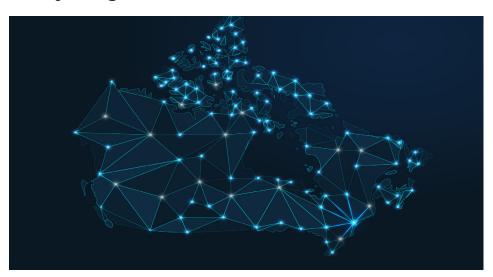


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For more information, visit: www.gnregistry.ca

Study Progress





Recruitment target: 300

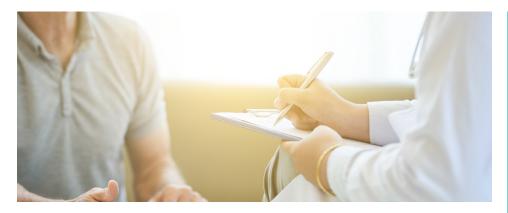
As of December 31, 2020, there are a total of **122** participants recruited! Due to the pandemic, recruitment stopped in March 2020 but restarted in September 2020. Over the last few months, the focus has been to follow up with the participants already enrolled in the study.



Recruitment by site

University of British Columbia	31
University of Calgary	1
University of Alberta	9
Sunnybrook	16
Toronto General Hospital	27
Ottawa Hospital Research Institute	14
Laval	9
Dalhousie University	6
MUHC	9

Follow-up Visit



Due to the restrictions during the pandemic, some of the possible follow-up visit scenarios that we have heard from you are as follows:

- In-person clinic visit but no research related activity was done
- Telephone clinic visit but no research related activity was done
- Telephone research visit but biospecimen was not collected
- In-person research visit outside of the clinic where biospecimen was collected but physical examination was not done

Irrespective of the visit type, kindly enter all relevant data in the study database as a scheduled visit (even if the visit date is outside of the study visit window) for the participant. Please know that you will be queried for data that requires clarification so we know the reason for deviation and/or missing data.

Future Directions

Protocol Amendment

- follow-up will be extended to three years.
 This will mean adding two more visits to the current follow-up time
- Visit window will expand to +/- 60 days
- Updated protocol will be circulated for your local REB approval

Databases

 The RAVE and REDCap databases will be updated to reflect the protocol amendment

For study questions and concerns, contact:

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