



**To: the Silent Genomes Indigenous Rare Disease Diagnosis (S-GIRDD)  
Steering Committee / IBVL Governance Committee**

**Re: Request for Research Proposal Review**

**Date:**

**Institution(s):**

**Investigators:**

*(please mention all investigators and co-investigators and include community affiliation)*

We are submitting a research proposal for your review:

*Project title*

We are proposing to utilize variant frequency data present in the Silent Genomes Project IBVL and/or other Silent Genomes project genomic data,

We have reviewed the [Silent Genomes IBVL Resource document](#).

The lay summary of the project is provided below

*250 word limit*

This project has been created in active partnership with Indigenous patients, families, communities and/or their designated organizations.

*Please describe in which way. If no partnership, please describe why. 250 word limit*

The best way to contact the Investigator is by:

*Email or phone number, hours and time zone*

Sincerely,

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*email:* \_\_\_\_\_

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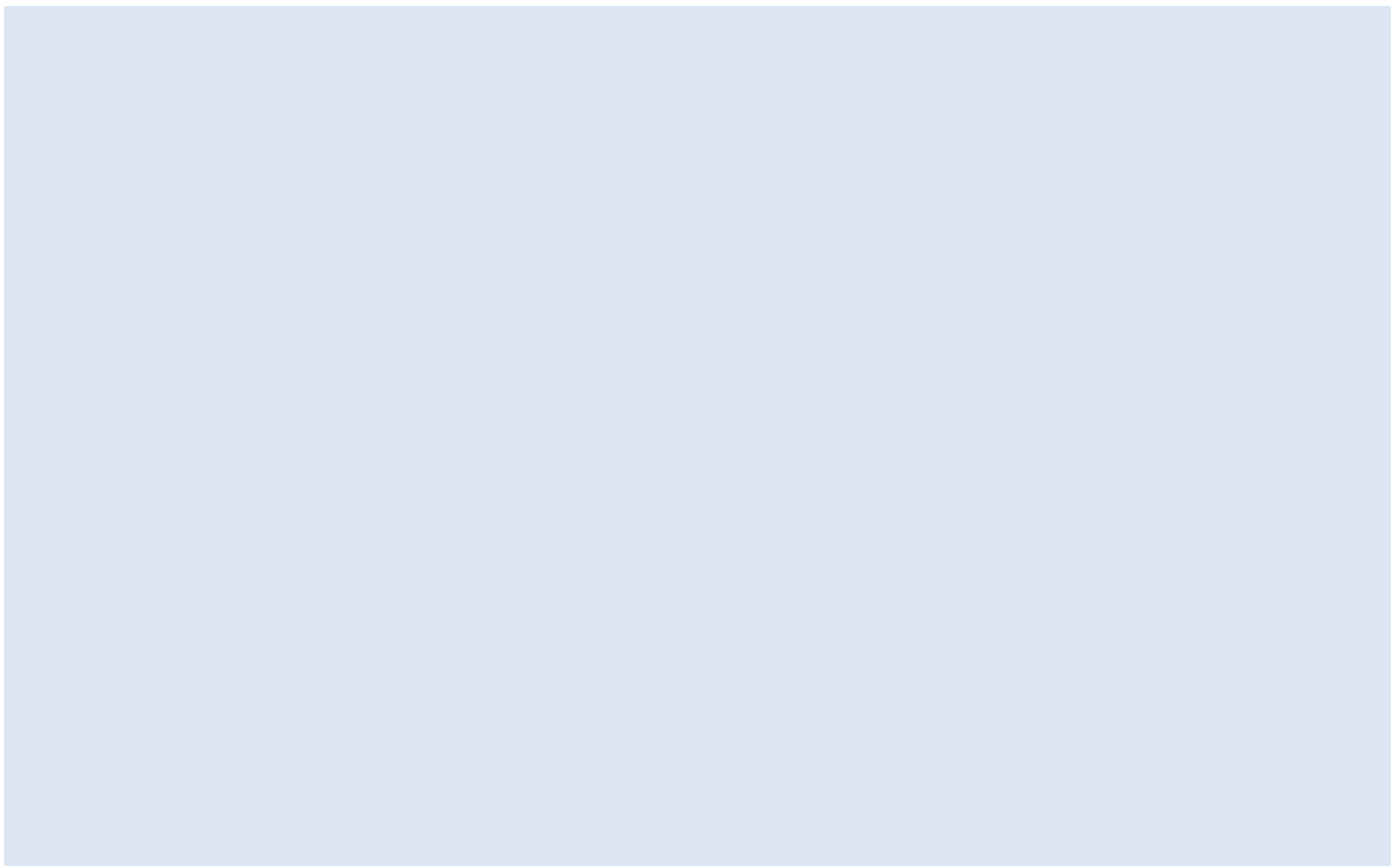
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*please do not fill this part until the committee responds whether the project is eligible for review*

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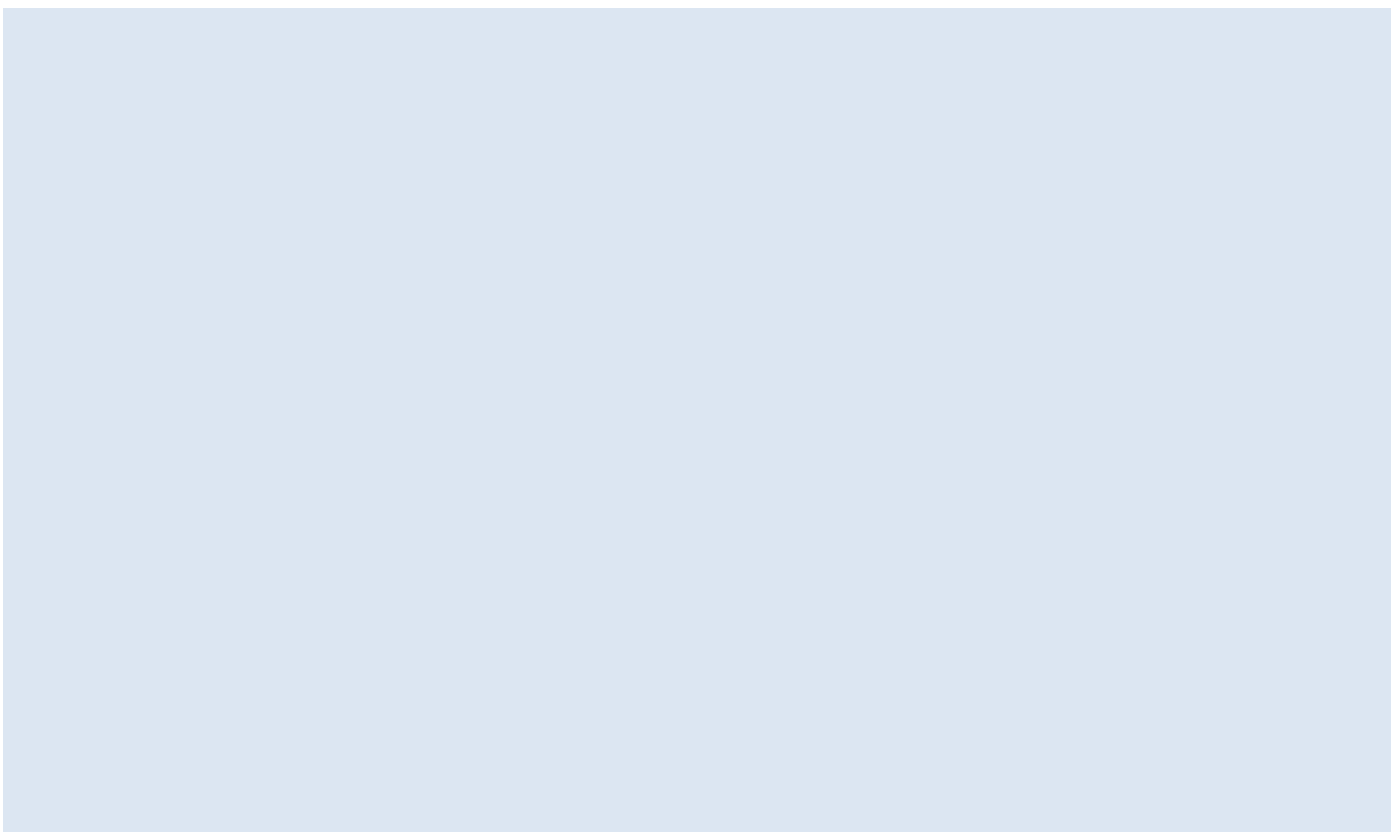
**S-GIRDD/SG-IBVL has found this project eligible for review**

**Please describe how the Silent Genomes variant information will be used**



*(up to one half page)*

**Please detail variant data request**



*(up to one half page)*

We confirm that,

This project is aiming to benefit Indigenous health.

*Please describe benefit to Indigenous patients, families, and/or communities. Please describe overall benefit of this work (250 words). Ideally, this paragraph is written or reviewed by the Indigenous partner*

Was this paragraph written or reviewed by the Indigenous partner?

Written

Reviewed

Neither

*Community members' comment (if available).*

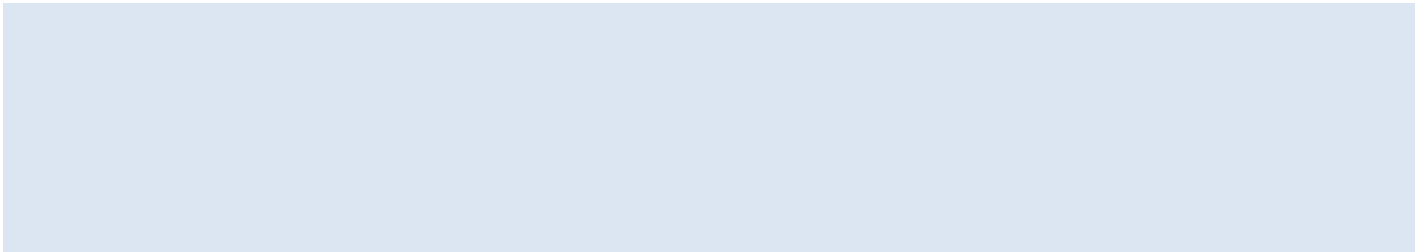
We understand and are aiming to avoid/mitigate potential risks of the project for Indigenous people.

*Please describe potential risks to Indigenous patients, families, and/or communities.*

The data will only be used for the project proposed (there will be no secondary use of data without additional review and approval);

Variant information will be protected

*Please detail risks associated with the data request. Please explain your understanding of the secondary use of data related to your request.*

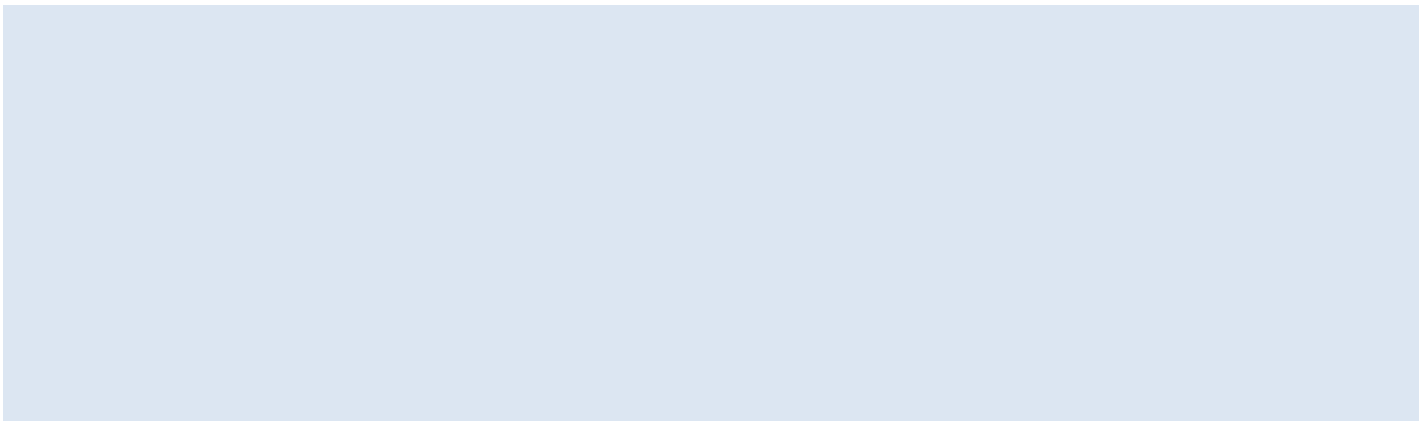


*Please provide details as to how the variant information provided will be protected*

Appropriate research ethics review process has been initiated:

Institutional Research Ethics Board (REB) submitted	Yes	No	N/A
Regional REB or Research license has been submitted	Yes	No	N/A
Community REB has been submitted	Yes	No	N/A

We are aware that additional approval review(s) may be required by participating communities, the Alliance for Healthy Hearts and Minds, or Indigenous organization(s).



*Please explain additional reviews undertaken , and/or planned to be taken*

A two-page proposal is attached (if attached, it will remain confidential)

Sincerely,

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