

SHO Cohort Data Access Procedures and Guiding Principles

Introduction

VIP Research Lab

The Vulnerable Individuals in Primary Care (VIP) Research Lab is committed to producing robust evidence for novel primary care and community-based interventions that: a) improve primary care access and linkage for vulnerable populations and b) that reduce inappropriate health care utilization.

It focuses on vulnerable populations that are under-represented in healthcare research because they are difficult to reach. It takes a specific approach which is cognizant of their vulnerabilities and uses methods which are time-consuming and more involved than traditional research.

We aim to integrate research into mainstream health practice and the broader health system by partnering collaboratively with patient groups, interest-holders, and primary care providers to develop programs specific to the unmet health needs of vulnerable populations.

The Social Housing of Ontario (SHO) Cohort

In order to identify priority health concerns of individuals residing in social housing, it was necessary to create a database or cohort of social housing sites. Over the course of several funded projects, Dr Gina Agarwal, Director of the VIP Research Lab, has developed the **Social Housing of Ontario (SHO) Cohort**. This cohort is securely stored and maintained at McMaster University and is composed of all social housing sites in Ontario that can be identified using administrative data.

This document outlines the principles, policies, and procedures that govern access to the SHO Cohort. These guidelines are designed to ensure that data access aligns with ethical conduct of research involving participants based on the principles outlined in the Tri-Council Policy Statement while also facilitating responsible data sharing to advance scientific knowledge and improve health equity.

Researchers requesting access to VIP Research Lab data must adhere to the Data Access Procedures and Guiding Principles described herein. Data access requests will be reviewed through a structured governance process to ensure that all research conducted aligns with the VIP Research Lab's commitment to ethical research, and meaningful contributions to healthcare policy and practice.

Guiding Principles of SHO Cohort Data Access Procedures

The VIP Research Lab will govern access to the SHO Cohort Data through a data application process and policy. SHO Cohort Request Form: <https://forms.gle/sx9QgwYEtvZy5Skb7>

- 1) All Applicants will be required to follow the Access Procedures.
- 2) Data Access Inquiries should be directed to Dr Gina Agarwal at the VIP Research Lab using the procedures outlined below,
- 3) All researchers seeking access to the SHO Cohort will be required to fill out the SHO Cohort Request Form: <https://forms.gle/sx9QgwYEtvZy5Skb7>
- 4) There is a two-step process if your research requires access to SHO cohort-linked administrative health data housed at ICES.
 - a) First, you must seek permission for data access from Dr Gina Agarwal by completing the **same** SHO Cohort Request Form ([link](#)) and procedures.
 - b) If approved, the permission will need to be attached to the ICES data request form before any data can be used.
- 5) Following completion of the SHO Cohort Request Form, further information may be requested, and requests will be assessed on a case-by-case basis.
- 6) Approved data requests will require completion of a Data Transfer Agreement between the VIP Research Lab, McMaster University and the researcher
 - a) SHO Cohort data will only be released to researchers once ethics approval for the research project has been obtained from the appropriate Research Ethics Board, and the SHO Cohort Access Agreement between the SHO Cohort Custodian and the Applicant's institution has been executed. In addition, the data will only be released once evidence of appropriate research funding to conduct the study is received.
- 7) After assessment and approval, SHO Cohort data will be made available for use in a timely and responsible manner taking into account the need to assure data validity.
- 8) Exclusive access rights to SHO Cohort data will not be granted to any Applicant for any Research.
- 9) The confidentiality and the security of SHO Cohort data **must** be safeguarded at all times.
- 10) Approved Applicants (Users) may be required to return derived variables and/or results to the VIP Research Lab within a timeframe specified in the Data Transfer Agreement. Users may be required to return to the SHO Cohort derived variables for inclusion in the SHO Cohort database for use by other researchers. In addition, Users may be asked to return derived variables if such variables are identified in annual progress reports or manuscripts emanating from use of the SHO Cohort data.
- 11) SHO Cohort data are resources that will be used optimally to support research to benefit vulnerable populations.



Intellectual Property

Any proposed project/work is based primarily on the research program and cohort creation developed by Dr. Gina Agarwal as the Principal Investigator from grants which funded the creation of the Social Housing Cohort. However, in recognition that ongoing and future work based on the SHO Cohort would include external researchers, any work stemming from this would have IP shared between the requesting user and Dr Gina Agarwal, VIP Research Lab. The VIP Research lab would like to promote the accessible distribution of knowledge developed with the Social Housing Cohort to maximize its benefit to the public. The VIP Research Lab encourages Users to share their results (including research tools) with the scientific community.

Financial Considerations

The VIP Research Lab funded the creation of the SHO Cohort. Access fees will be based on a cost recovery model for the review of the application while ensuring adherence to the guiding principles, and if acceptable, data access. An application fee will be payable to McMaster University. If your research requires access to SHO cohort-linked administrative health data held at ICES, there will be a separate fee from ICES for that data access.

Publications and Acknowledgement in Publications

All publications or presentations resulting from the collaborative research as detailed in the Project and undertaken must reflect this primary contribution by listing the McMaster Principal Investigator as an author. The collaborative nature of the Project conducted shall be recognized in all such academic outputs.

Authorship and Acknowledgement Statement

Researchers will be required to comply with authorship and acknowledgement policies, detailed in a Data Sharing Agreement.

Contact Information

For further information, please contact Melissa Pirrie, Research Associate pirrie@mcmaster.ca