

# Guidelines for Research Involving TVCC Clients

## Objective

TVCC supports quality research studies that involve clients and their families. We will work with researchers to determine the types and levels of in-kind and paid support we can provide for individual studies.

## Scope

These guidelines apply to studies where TVCC staff will be contacting clients and families to ask about their interest in participating in studies.

For studies being done through contracted service providers rather than TVCC staff, it is up to the service provider to ensure that appropriate ethics approvals and consent processes are in place.

General 'passive' recruitment – such as sharing a flyer with families, allowing them to choose to contact a researcher or not – needs only the approval of the Director of Quality Management.

For TVCC staff asked to be subjects in research studies, the decision to participate or not is up to each individual person, with the decision about whether it is done on paid worktime or not resting with their Manager or Director.

## Project Approval

All research studies involving active recruitment of TVCC clients and/or their families must have approval from the Director of the relevant TVCC services and the Director of Quality Management.

## University Ethics Approval

TVCC will review applications that do not yet have approval from a university ethics review committee, but any approval given will be conditional upon the TVCC Research Officer receiving a copy of the signed approval letter before the study may begin.

## Expectations of Approved Projects

The TVCC Research Officer must be notified of any significant changes to approved studies and any ethics amendments approved through the university review committee must be submitted.

A condition of approval for all projects is that within six months of completion of the study the investigator(s) will

- complete a TVCC Project Status Report outlining the findings and clinical impact,
- disseminate their results to participants,
- provide the TVCC Research Officer with information about any publications and presentations, and,
- present the study findings to TVCC staff.

## Application Procedures

Researchers will talk with the relevant TVCC Director or Manager about their study, and then submit the Research Study Application form (available at at [www.tvcc.on.ca/research-project-approval](http://www.tvcc.on.ca/research-project-approval)) to the Research Officer at [research@tvcc.on.ca](mailto:research@tvcc.on.ca).

The Director of Quality Management and the Director of the relevant TVCC service will follow up with the researchers about any outstanding questions. When details are finalized to everyone's satisfaction, the application will be approved.

If the study will be paying for TVCC staff time, the Research Officer will send the researchers the [template for an agreement](#) about that payment and invoicing, to be signed by them and the relevant Director who will then complete a [Request for Research Account form](#) and submit to the Business Office with the signed agreement.

## Research Contact Person

TVCC will not release names or contact information for clients or their families to external researchers without explicit consent. The first contact about a study must be done by a TVCC staff member, as identified in the project application form with the approval of the relevant clinical program Director.

The Research Contact is a TVCC staff person responsible for facilitating the research process, coordinating participant recruitment, and contacting potential participants. It is done as part of the individual's regular work duties at TVCC and is typically provided in-kind by TVCC.

The investigator is responsible for getting informed consent for participation in the study. The Research Contact is getting consent to share contact information with the investigator.

## Responsibilities

The Research Contact will

- talk with Clinical Information Services about how best to identify clients who meet the study's inclusion and exclusion criteria,
- contact those clients and/or families, sharing preliminary information provided by the investigator about the study, and,
- with consent, sharing contact information of the client with the investigator.

Any questions about research at TVCC can be directed to the Research Officer or the Director of Quality Management.