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CanROC
Canadian Resuscitation Outcomes Consortium
Consortium Canadien de Recherche en Réanimation

## How does CanROC Work?

The Canadian Resuscitation Outcomes Consortium is a cross-country research collaborative. Membership includes paramedic and fire services across Canada, with research oversight from hospitals and universities. The CanROC database is located at St. Michael's Hospital in Toronto, Ontario.

Together, Scientific Investigators representing each CanROC regional site have developed the CanROC Registry research protocol. The CanROC Registry study follows cardiac arrest and severe trauma for patients suffering injury or illness outside of a hospital setting, treated by participating paramedic or firefighter services (see the CanROC Governance and Collaborator webpages for a list of participating organizations).

The CanROC Registry study has the following primary objectives:

- Report current performance and guide future emergency medical services (EMS) and in-hospital care
- Provide a resource for observational studies
- Support interventional trials
- Improve outcomes of adult and paediatric patients after cardiac arrest

Secondary objectives include:

- Evaluate relationships between outcome and regionalized patient care systems, identify best practices, and report compliance with resuscitation guidelines and current evidence
- Enable cost-effective pragmatic trials launched quickly and broadly across Canada using the existing CanROC Registry infrastructure
- Expand CanROC Registry data collection to provide provincial and national datasets
- Examine relationships between public policy and health outcomes, and describe epidemiology of acutely ill patients

## How does CanROC help Canadians?

Major traumatic injury leads to nearly 13,000 deaths each year, and out-of-hospital cardiac arrest has a mortality rate as high as 95% in some communities. By working towards the above objectives, CanROC Registry provides a wealth of data that can be used to identify practices that result in improved survival and functional outcomes for these patients.

In addition to identification of best practice, CanROC Registry can provide targeted feedback to individual regions and agencies to provide performance indicators and benchmarks to work towards those best practices.

Finally, studies done using the CanROC Registry data will contribute to the scientific literature world-wide, helping to improve patient outcomes both locally and abroad.

## How does CanROC collect data?

Before any data can be collected by a CanROC site, the CanROC Registry study protocol is first approved by local Research Ethics Boards (REBs). These REBs review any study involving human subjects, which is critically important in CanROC Registry since obtaining consent is not feasible for patients in life-threatening situations. The REB-approved study protocol is also referenced in agreements with each

participating hospital or EMS agency, allowing the CanROC research team to collect the health data collected by clinicians.

CanROC research staff work with the participating organizations to access patient charts and collect the CanROC Registry study data. This data is entered into a secured database at St. Michael's Hospital, which has undergone extensive validation and security and privacy assessments. No Identifying information (such as name, health card, or date of birth) is collected.

## Who can see the CanROC Registry data?

The study data is only available to the organizations that collected it, and the CanROC research team. Any time researchers want to present the data at conferences or in publications, they must make a request outlining the data variables. The CanROC Data Access Committee will then review each request.

CanROC Registry only includes data that is routinely captured by paramedics, firefighters, or hospital staff, during routine course of care. If patients or their next of kin wish to view their study data, they should contact the organization that provided care and performed initial medical documentation.

## Who decides how the data can be used?

CanROC can only use data from the CanROC Registry study as permitted by the Research Ethics Boards that approved the study protocol. The CanROC Publications Committee works with the Data Access Committee (DAC) to ensure uses of data are in line with REB-approved usage.

The Data Access Committee (DAC) is comprised of CanROC investigators, and must contain at least one privacy representative from St. Michael's Hospital, and at least one community member that is not otherwise affiliated with CanROC. The DAC then reviews each request to ensure it is in line with one of the REB-approved study objectives. The DAC also ensures that releasing the data will not subject any individual or groups of patients to possible harm or stigmatization. Finally, the committee will ensure that only the minimal required data is released, and that it is sufficiently de-identified.

If the vote is not unanimous, the data request will be rejected and must be restructured, or may require addition Research Ethics Board approval.

CanROC believes that transparency is an important part of protecting Canadians' rights in clinical research. We encourage you to browse www.canroc.org for more information, or contact CanROC@smh.ca if you have further questions.