

**DIABETES ACTION CANADA**  
**NATIONAL DIABETES RESPOSITORY**

Subject	Research Governance	TOR#	Diabetes Access Canada NDRSOP- RGC002
Document Number	2.0	Author	Conrad Pow
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## 1. GENERAL INFORMATION

The Research Governing Committee (RGC) for the SPOR Diabetes Action Canada’s (DAC) National Diabetes Repository (NDR) is an operating committee that plays a critical role in the decision-making process. It strives to ensure secure access to data for users consistent with DAC’s mission, while maximizing opportunities for patient and health provider engagement. Involving patients and providers in governance activities, including the review of research applications, builds DAC’s capacity to perform patient-oriented research.

## 2. MANDATE

The RGC oversees the use of the data in the NDR and has decision-making authority regarding individual studies that have been submitted. The RGC will act as a resource to DAC and will make recommendations to the Operations/Management Committee regarding revisions to policies. The RGC will ensure that there is quality and continuous learning in the governance process by ensuring data access policies and processes are in place, working appropriately, and reviewing how well the data are able to accommodate the research questions being posed.

## 3. PROJECT REVIEW

The Research Governing Committee will review all applications requesting access to the National Diabetes Repository. All projects submitted will first be reviewed by the NDR Sr. Project Manager and Data Manager. They will review the projects feasibility, ensuring that the data and terms of the methods are appropriate for the question(s), sufficient funding is obtained, and study team meets the criteria. Once this has been completed the project will be forwarded to the RGC for review and approval.

The RGC will evaluate projects on the following criteria:

- 1. Project Importance:** The project should aim to improve outcomes in primary health care. It should answer question(s) that are currently being faced by clinicians and/or their patients. It should have the potential to improve patient health and/or health services. It should facilitate and encourage innovation and excellence in diabetes research.
- 2. Methodological Quality:** Where a credible methodological review has been completed by a scientific peer committee (e.g. by CIHR), the project will not need a methodological review by the RGC. If the project has not had a credible review completed, then a formal review must be completed by the DAC Scientific Advisory Committee with feedback presented to the RGC for review.

**6. Patient Perspective:** The project must be designed in the best interests of the patients. The RGC patient representatives should have a clear understanding of the project's aim/goals and how the results will be communicated back to the patient population.

## 5. MEMBERSHIP

There will be 14 members, including two co-chairs and two non-voting members. The RGC will include:

- a) Six people with experience of living with diabetes. They will represent 50% of the RGC.
- b) Two Physicians/other data provider representatives
- c) Two Researchers with relevant experience in health services research and/or advanced analytics
- d) Two individuals knowledgeable in ethics, privacy, and relevant law
- e) One DAC NDR Representative (non-voting member)
- f) One administrative staff (non-voting member)

There will be two co-chairs; one of these will be from among the patient representatives (a) and the other from amongst those in (b) through (d) above.

Subject matter experts may be called upon, as required to address specific issues when members do not have the expertise.

## 6. TERM

RGC members will be appointed for a term of three years. After the first year, each co-chair will be required to have served one year on Committee before taking office.

## 7. MEETING FREQUENCY

The RGC will meet quarterly and meetings will last 1-2 hours. At the first two meetings the following are required: a researcher, an individual knowledgeable in ethics and in privacy and 50% of members +1.

## 8. REPORTING/ACCOUNTABILITY

The RGC will be accountable to the Steering Council. It will also report to Operations/Management Committee via the DAC NDR Representative. The RGC will provide routine updates to the to the Steering Council (annually) and Operations/Management Committee (quarterly).