

**DIABETES ACTION CANADA
NATIONAL DIABETES RESPOSITORY**

Subject	Fee Structure	SOP#	Diabetes Access Canada NDRSOP-FS002
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1. GENERAL INFORMATION

The aim of this standard operating procedure (SOP) is to outline fees associated with conducting a project in the Secure Analytic Environment within the Diabetes Action Canada National Diabetes Repository. Diabetes Action Canada is not-for profit research, CIHR and partner-funded consortium. Fees are calculated strictly on a cost recovery basis.

2. SCOPE

This document is intended for researchers wishing to plan cost and access to data housed in Diabetes Action Canada's National Diabetes Repository.

3. ROLES AND RESPONSIBILITIES

3.1 Diabetes Action Canada Repository Manager: Responsible for the overall operations (recruitment, developing policies and procedures, site relationship) and communication regarding the Diabetes Action Canada Repository.

3.2 Diabetes Action Canada Repository Data Manager: Responsible for data extraction, processing, quality check, destruction, reports, transfer, secondary data usage, and managing the data dictionary; responsible for updating the Diabetes Action Canada Repository Manager on changes or problems with the Diabetes Action Canada Repository.

3.3 Diabetes Action Canada Repository Research Coordinator: Responsible for managing the participant database and facilitating meetings with the Scientific Advisory Committee and Research Governing Committee.

3.4 Diabetes Action Canada Researcher: Responsible for ensuring that all project team members, including self, are familiar with the Diabetes Action Canada Policies and Procedures pertaining to the National Diabetes Repository. Will be responsible for ensuring that all project team members have signed the Conflict of Interest statement. Will be responsible for the management and oversight of the project.

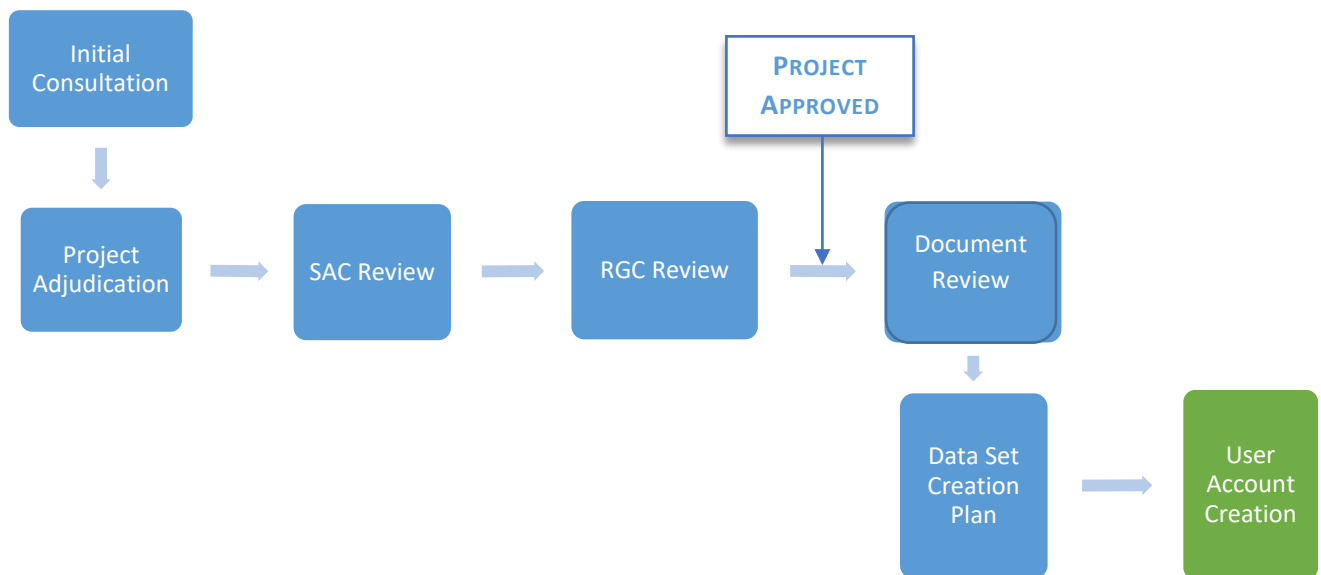
3.5 Diabetes Action Canada Repository Scientific Advisory Committee (SAC): The SAC is made up of 3 members. The SAC is responsible for reviewing projects proposing to access data in the Diabetes

Action Canada Repository. The SAC will review the scientific merit and methodology of the project.

3.6 Diabetes Action Canada Repository Research Governing Committee (RGC): The RGC will ensure that the focus of the proposed project is aimed at what is in the best interest of the patient and aligns with Diabetes Action Canada’s mission and values.

4. DATA AND SERVICE COSTS

The figure below provides an overview of the stages of the Project Approval:



- 1) **Initial Consultation and Project Adjudication:** provides an opportunity for researchers to obtain early consultation on the project’s feasibility and cost estimate. The cost estimate will be based on rough parameters of the project.
- 2) **Scientific Advisory Committee Review:** is responsible for reviewing projects proposing to use data in the Diabetes Action Canada Repository. It will review the scientific merit and methodology of the project. Once approved, the application will be forwarded RGC. This step can be consolidated with the RGC review.
- 3) **Research Governing Committee Review:** will ensure that the focus of the proposed project is aimed at what is in the best interest of the patient and that aligns with Diabetes Action Canada’s mission and values.
- 4) **Document Review:** Ensure project documents and agreements are fully executed.
- 5) **Data Set Creation Plan:** The Data Manager will work with the Researcher to review and filter the cohort definition and data elements. Costs are determined by number of fields requested and whether complex computing is required.
- 6) **User Account Creation:** The Researcher’s account will be created to allow access to the requested data in the secure analytical environment. Please note that depending on user’s eligibility and request for statistical software, additional fees maybe applicable.

- 7) **Data Analysis Support (optional):** The Data Analyst will provide support by conducting statistical analysis of the research data of the project. This is an optional service that researchers can request should they need analytical support for their research data. This is mandatory for research teams that do not have experience using electronic medical record data.

50% of the Cost Estimate will be provided by the Researcher up front for the project to commence. If the cost of the conducting the project increases more than 10% during analysis, the Researcher will be notified in writing and the project will be placed on-hold until the Researcher acknowledges and approves the increase. The final invoice with the actual project costs will be provided to the Researcher at the completion of the project and will be due prior to the transmission of the final research outputs to the Researcher.

5. FEE SCHEDULE

The data and service cost will be determined by the projects needs including the depth of the data, software required, or extra analysis required. The amounts listed in the table below reflect per project costs and hourly rates where noted). Refer to Cost Estimation Worksheet for approximate cost of the project.

DATA ACCESS COST



PROJECT COST ESTIMATOR				
Resources	Hours	Current Rate (CAD)	2020/2021	TOTAL
1. Project Adjudication	2	265.00	265.00	530.00
2. RGC Review	1	1,100.00	1,100.00	1,100.00
3. Legal Review	1	300.00	300.00	300.00
4. Data Creation Plan	2	95.00	95.00	190.00
5. Data Analysis	0	95.00	125.00	-
6. Data Cut	Standard	95.00	98.80	370.50
7. Research Environment	1	300.00	Sub-Total	2,790.50
TECHINICAL COSTS			20% Overhead	558.10
Account Type	Required	Total	Total	3,348.60
Python	Yes	in-kind		
Rstudio	Yes	in-kind	Technical Costs:	650.00
SAS	No	-		
SPSS	Yes	500.00	Project Grand Total:	\$3,998.60
Stata	No	-		
VPN Account Creation		150.00		
	Total	650.00		
Additional accounts	0	\$ -		
Educational Adjustment		\$ -		
	Total	\$ 650.00		

Please note: Projects will be reviewed on a case-by-case basis. The example above is the minimum project cost. Projects from private sector researchers will require additional legal review and data analysis costs.

6. DEFINITIONS AND ABBREVIATIONS

<i>Organizations</i>	
CAC (Centre for Advanced Computing)	The Centre for Advanced Computing located at Queen's University, specializes in secure, advanced computing resources and support for academic and medical clients. It is the home of the National Diabetes Repository.
SPOR (Strategy for Patient-Oriented Research)	Patient-oriented research refers to a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes. The objective of SPOR is to foster evidence-informed health care by bringing innovative diagnostic and therapeutic approaches to the point of care, to ensure greater quality, accountability, and accessibility of care.
<i>Technical terms</i>	
Data providers	Data providers are health care providers who participate in contributing their EMR data into the National Diabetes Repository. Currently, all our data providers are family physicians. In the future, data providers may extend to other groups that hold patient-level information (including imaging).
RGC (Research Governing Committee)	The Diabetes Action Canada Governing Committee is comprised of 50% patients and 50% professionals and subject experts. They are responsible for overseeing the use of the data in the NDR. They review and approve all projects before access is granted.
Responsible DAC Researcher	Non-DAC Researchers proposing to conduct a project in the NDR must have a Responsible DAC Researcher assigned to the project. The Responsible DAC Researcher will ensure policies and procedures are adhered to. A list of DAC Researchers can be found here: https://diabetesaction.ca/category/investigators/