



## Frequently Asked Questions

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**Only non-identifying, aggregated analysis results are shared. Individual level data or variables are not shared to support analyses.**

**Question #1: Who or what organizations are able to request access to data analysis results from the CAPACITY Registry?**

**Answer:** At this time, only CAPACITY members (including members of CAPACITY advisory boards and committees) and individuals from a CAPACITY affiliated institution may request access to data analysis results from the CAPACITY Registry. A Co-Principal Investigator or Co-Investigator named on the original grant must be listed as a Co-Applicant on a request.

Non-CAPACITY members, students, and trainees who wish to request access to data analysis results will need to include a CAPACITY Co-Principal Investigator or Co-Investigator as part of their request. That person will need to co-sign the request, and will act as the primary requestor / project supervisor.

**Question #2: How do I know what variables are available for analysis in the CAPACITY Registry?**

**Answer:** The “Explore Variables” page of the CAPACITY data portal includes a list of the available registry variables, including both individual and visit level diabetes data from participating centres / registries across Canada:

- **Patient level data** is collected once, and includes variables such as date of diabetes diagnosis, diabetes type, and presentation at onset.
- **Visit level data**, such as blood pressure, laboratory results, insulin regimen, and diabetes complications, is collected at each clinic encounter and is updated at least twice a year. Visit level data is captured until patients transition to adult care (at approximately 18 years of age).

**Question #3: How far back does the data go?**

**Answer:** Data from 2015 onwards is included in the registry, dependant on when local data collection began at each of the participating centres / registries across Canada (some centres / registries may have begun collecting data after 2015).

**Question #4: How long will it take for the Access Request Committee (ARC) to make a decision regarding my request to access data analysis results from the CAPACITY Registry?**

**Answer:** The CAPACITY Coordinator will follow up with requestors within two weeks of receiving an access request (this will be done through the CAPACITY Data Portal). They will confirm whether the access request contains all required elements. Requestors will be asked to provide any missing information or documentation.



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The Access Request Committee (ARC) meets at least quarterly, and more frequently based on the volume of requests. Following the review of an access request, a notification will be sent to requestors.

**Question #5: Who should I contact if I have questions regarding the status of my application?**

**Answer:** Requestors will be able to **track the status of their application by going to the CAPACITY Data Portal** and selecting their access request. The access request dashboard summarizes the status of the request and any actions that are required from the requestor. A notification will be sent to the requestor once a decision has been made.

Any other questions regarding the application process or the CAPACITY registry can be directed to the CAPACITY Coordinator at the Research Institute of the McGill University Health Centre (RI-MUHC), via email ([capacity.data@muhc.mcgill.ca](mailto:capacity.data@muhc.mcgill.ca)).

**Question #6: Are there fees associated with requests to access data analysis results from the CAPACITY registry?**

**Answer:** A **cost-recovery fee** will be charged for successful applications. Fees will be used to cover costs associated with the analysis of data and the ongoing maintenance of the CAPACITY Registry infrastructure. Fees will not be a source of profit for CAPACITY team members or their associated institutions.

Following the review of a request to access data analysis results, a **cost estimate** will be provided based on the anticipated time needed to review the application and perform the analyses (unless the requestor is requesting access to DataShield to perform analyses themselves). The actual amount charged may vary and will be confirmed after the analyses have been completed.

We understand that researchers may need to budget data costs into **grant applications** and may require a quote for that purpose (without the need to access data analysis results). Individuals wishing to inquire about such costs should submit an access request, and indicate this in **Funding** section.

Additional costs may be incurred in relation to amendments made to the original, approved access request. Any updates made to the original cost estimate will be communicated to the requestor before implementing any updates.

**Question #7: For how long will I have access to data analysis results or DataShield analysis tools? Is there a time limit? Can the data be used for other purposes?**

**Answer:** Requestors will have access to data analysis results or DataShield analysis tools for the specific time and uses agreed upon. If they wish to extend the time originally specified or use the data for additional purposes, an amendment to the original data request will need to be submitted.



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**Question #8:** How should the results of my project be shared?

**Answer:** All outputs, including publications, abstracts, presentations, lay summaries and knowledge translation documents, should cite the CAPACITY registry as follows:

[Author List], [[Name of Paper or Document]: “*Data from the CAPACITY Registry.*”],  
[Journal or Document Name] [Year]

**Outputs must be reviewed and approved by the CAPACITY Projects Committee prior to publication. The Projects Committee will provide related guidance, feedback and oversight, and written approval to proceed. Those accessing CAPACITY registry data will work in collaboration with the Knowledge Translation and Advocacy Subcommittee to translate and share what is learned with partner groups.**