

APPLICATION FOR ACCESS TO CANADIAN CYSTIC FIBROSIS REGISTRY DATA

A. GENERAL INFORMATION

PRINCIPAL INVESTIGATOR				
Title / Titre <input type="checkbox"/> Dr. <input type="checkbox"/> Mr. <input type="checkbox"/> Ms. <input type="checkbox"/> Prof.		Given Name	Middle Name	Surname
Position				
MAILING ADDRESS OF PRINCIPAL INVESTIGATOR				
Institution		Department or Faculty		
Street Address		Suite or Floor (if applicable)		
City	Province	Postal Code	Email	
Office Telephone Ext.		Lab Telephone Ext.	Fax	
TITLE OF PROJECT				
HOST INSTITUTION				
GRADUATE PROGRAMS				
Is this project part of a graduate training program? <input type="checkbox"/> Yes <input type="checkbox"/> No				
If yes: <input type="checkbox"/> Master's <input type="checkbox"/> PhD		Name of Supervisor:		
ADDITIONAL INFORMATION				
Type of Canadian Cystic Fibrosis Registry data requesting: <input type="checkbox"/> identifiable patient data <input type="checkbox"/> de-identified patient data <input type="checkbox"/> summary data				
What statistical package will you be using (e.g. SAS)?				
What is your preferred format for the data (e.g. Excel)?				
Has Research Ethics Approval been obtained for this study? <input type="checkbox"/> Applied for <input type="checkbox"/> Yes (attach copy of approval)				
SIGNATURE				
Principal Investigator Name		Signature	Date	

B. LIST ALL INDIVIDUALS ASSOCIATED WITH THE PROJECT WHO WILL HAVE ACCESS TO THE DATA

Title <input type="checkbox"/> Dr. <input type="checkbox"/> Mr. <input type="checkbox"/> Ms. <input type="checkbox"/> Prof.	Given Name	Middle Name	Surname
Institution		Department or Faculty	
Street Address		Suite or Floor (if applicable)	
City	Province	Postal Code	

Title <input type="checkbox"/> Dr. <input type="checkbox"/> Mr. <input type="checkbox"/> Ms. <input type="checkbox"/> Prof.	Given Name	Middle Name	Surname
Institution		Department or Faculty	
Street Address		Suite or Floor (if applicable)	
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Title <input type="checkbox"/> Dr. <input type="checkbox"/> Mr. <input type="checkbox"/> Ms. <input type="checkbox"/> Prof.	Given Name	Middle Name	Surname
Institution		Department or Faculty	
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Title <input type="checkbox"/> Dr. <input type="checkbox"/> Mr. <input type="checkbox"/> Ms. <input type="checkbox"/> Prof.	Given Name	Middle Name	Surname
Institution		Department or Faculty	
Street Address		Suite or Floor (if applicable)	
City	Province	Postal Code	

Please append additional copies of Page 2 if there are more than four Co-Investigators and/or Collaborators.

D. SUMMARY OF PROPOSED RESEARCH

Please provide a summary of the rationale, general objectives, methods and specific goals of the proposed research. (max 2 pages)

[Empty box for providing a summary of the rationale, general objectives, methods and specific goals of the proposed research.]

D. Continued SUMMARY OF PROPOSED RESEARCH

[Empty box for continued summary of proposed research]

E. DETAILS OF REQUEST FOR CANADIAN CYSTIC FIBROSIS REGISTRY DATA

Please provide specific details about type of Canadian Cystic Fibrosis Registry data requested (cross-sectional vs. longitudinal), specific years requested, list of clinical variables requested.

F. STATEMENT OF RELEVANCE

Applicants must describe in specific terms the relevance to, and potential importance, of the proposed research to cystic fibrosis. (max 250 words)

G. DATA LINKAGE

Describe, in detail, any plans for linking the Canadian Cystic Fibrosis Registry data to other registries/databases (e.g. administrative databases, CIHI, ICES etc). (max 250 words)

H. FEASIBILITY OF PROPOSED RESEARCH

Please provide a summary describing the feasibility of your project. (max 250 words)

I. DATA MANAGEMENT

Please describe how the Canadian Cystic Fibrosis Registry Data data will be managed, specifically methods for data management, storage, security and return/disposal of data upon completion of the project. (max 250 words)

J. CONFIDENTIALITY OF PROPOSED RESEARCH

Please describe the methods of ensuring preservation of confidentiality of patient information over both the short and long term. Also, if requesting identified data, please explain why this is necessary for the proposed research.