Cystic Fibrosis Canada
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APPLICATION FOR ACCESS TO CANADIAN CYSTIC FIBROSIS REGISTRY DATA

A. GENERAL INFORMATION

PRINCIPAL INVESTIGATOR			
Title / Titre ◯ Dr. ◯ Mr. ◯ Ms. ◯ 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 and Ext	Lab Telephone and Ext	Fax	
TITLE OF PROJECT			
GRADUATE PROGRAMS			
Is this project part of a graduate training program? ◯ Yes ◯ No			
If yes: ◯ Master's ◯ PhD	Name of Supervisor:		
DATA TRANSFER HOST INSTITUTION			
DATA TRANSFER CONTACT (if different from Principal Investigator)			
Name	Email		
ADDITIONAL INFORMATION			
Type of Canadian Cystic Fibrosis Registry data requesting: ◯ identifiable patient data ◯ de-identified patient data ◯ summary data			
What statistical package will you be using (e.g. SAS)?			
Has Research Ethics Approval been obtained for this study? ◯ Applied for ◯ Yes (attach copy of approval) ◯ N/A			
SIGNATURE			
Principal Investigator Name	Signature	Date	

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

Title ○ Dr. ○ Mr. ○ Ms. ○ Prof.	Given Name	Middle Name	Surname
Institution		Department or Faculty	
Street Address		Suite or Floor (if applicable)	
City		Province	Postal Code
Email			

Title ○ Dr. ○ Mr. ○ Ms. ○ Prof.	Given Name	Middle Name	Surname
Institution		Department or Faculty	
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Title ○ Dr. ○ Mr. ○ Ms. ○ Prof.	Given Name	Middle Name	Surname
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Title ○ Dr. ○ Mr. ○ Ms. ○ Prof.	Given Name	Middle Name	Surname
Institution		Department or Faculty	
Street Address		Suite or Floor (if applicable)	
City		Province	Postal Code
Email			

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

C. ACADEMIC BACKGROUND OF APPLICANT

The Principal Investigator must complete a copy of this academic background form.

Full Name
(Title, Given Name, Middle Initial, Surname) _____

Nationality _____

Education

Degree/	Date received	Discipline	Institution	Supervisor (if applicable)

Research training (post-doctoral)

Dates	Institution	Department	Supervisor

Academic positions held and hospital appointments

Dates	Institution	Department	Position

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)

D. SUMMARY OF PROPOSED RESEARCH (continued if needed)

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. Please note that unless otherwise requested and approved, a study-specific ID will be generated to uniquely identify individuals in the data.

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) as defined in the *Application Guidelines for accessing Canadian CF Registry data* document. Please also specify variables that will be required for linkage (e.g. name, birthdate, Canadian Cystic Fibrosis Registry ID number) (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.