Quebec Pain Registry ("Registry")

Access Policy and Use of Data ("Access Policy")

I. Context

The Registry is an administrative and research database of chronic pain patients that uses common demographics, identical clinical descriptions and uniform, validated and standardized measurement tools that may be used in promoting evidence-based standards of care. The database is available to facilitate and stimulate clinical pain research for both academia and industry and to provide a greater understanding of the impact of chronic pain on society. The Registry wishes to allow members of scientific community access and use of the data to carry out research.

II. Objective

The Access Policy is to oversee applications to be made by researchers wishing to use data (Data Requests). To be authorized, such use must be made in accordance and in compliance with this policy.

III. Conditions for use of Data

Access to data and data use should made in compliance with the following conditions

1. Ensure protection of the privacy of the Registry participants. Personal information is confidential. No access to non-anonymized data will be granted
2. The data is available for persons who carry out research activities, both in the academic sector (e.g.: universities and research institutes) and in the private sector (industry). Industry cannot sell the results of the data to another organization.
3. Before access is granted to the Registry, the applicant or research project must obtain approval from the Quebec Pain Registry Scientific Review Committee (SRC) by submitting a Data Request Form.
4. Once approved, any substantive change in study design that the applicant wishes to make must be transmitted to the SRC. Changes in data required will be handled as separate requests.

All information relating to an access request will be kept confidential.

IV. Scientific Review Committee

The Registry has created a Scientific Review Committee (SRC) and gives this committee the mandate to ensure respect for the Access Policy with respect to any request and use of data and to ensure its scientific integrity.

V. Processing a Request

i. The applicant who wishes to use the Registry data must make a written (or electronic) request to the Registry using the **Data Request Form** and send it to the SRC.

ii. Demand for access is considered "under review" until it is determined if the data or reports can be available according to the SRC criteria set in accordance with Registry objectives.

iii. The SRC recognizes that reviews of requests should be conducted in a timely manner.

iv. A decision in favor of the request, provided in a letter of understanding, will be followed by a use of "**Data Access Agreement**"

v. A decision to deny access to the Registry may include suggestions to the applicant of changes that could bring the request for access or use to a favorable decision.

VI. Criteria for Evaluation of a Request

The Scientific Review Committee must evaluate all requests for access with the following criteria:

i. Compliance with the terms and conditions listed in Section III (Conditions for use of Data)

ii. The scientific quality of the research project for which the application is associated, including;

a. The validity of the hypothesis;

b. The objectives of the research project;

c. The purpose and intended use of data

VII. Access, Use of Data and Delivery

i. Any applicant, whose request for access has been approved, will be provided with a "**Data Request Fee Estimate"** which will detail the costs and expected time frame of output.

ii. If agreeable the applicant must complete and sign a standardized "**Access Agreement**" before any data extraction can begin.

iii. The arrangement for data transfer, prioritization and delivery timing will be finalized by the Registry data management staff.

VIII. Publication

i. Applicants (researchers) who have used or accessed data are invited to publish the results of their project to the scientific community and the general public who may benefit from them. The researcher must state in its publications or presentations that the data used came from the Quebec Pain Registry. (See Schedule 1 of Access Agreement)

IX. Intellectual Property

The Registry does not claim any intellectual property rights on the results, discoveries, inventions or works that could result from a project research for which Registry data were used.

X. Costs

A non refundable administration fee is required for any applicant who submits a request for access. This cost is due when the request is submitted. This fee is to cover review costs and to discourage frivolous requests. It is only charged once per request.

Subsequent fees are required if an applicant is granted access and decides to proceed with use. The fees will be indicated on a **Data Request Fee Estimate** that will be provided to the applicant. These cost recovery fees include paying the cost of data preparation and extraction, statistical analysis (if applicable) and report production (if applicable) as well costs costs to operate the Registry.

XI. Exceptions and Special Circumstances

These policies are intended to serve as a guide to all interested parties on the routine access and use of Registry data. It is recognized that every circumstances that might arise cannot be anticipated. Any requests for consideration of special circumstance or exemption to the stated policies must be presented to the Registry in writing to the SRC who will render judgment.