



**TERMS OF REFERENCE
BONE AND JOINT HEALTH REGISTRY
TOPIC EXPERT GROUP**

Background and Purpose

The Alberta Bone and Joint Health Registry's Topic Expert Group is an interdisciplinary body that provides advice to the Registry's Governance Committee on matters related to the collection and use of Registry data, and reports on volumes and trends and on epidemiological findings.

Alberta Bone and Joint Health Registry Topic Expert Group Mandate

The Alberta Bone and Joint Health Registry Topic Expert Group is mandated by the Governance Committee to examine all issues related to the collection and use of Registry data and to analyze and interpret Registry data to identify patterns, causes, and effects of disease and health conditions related to the topic. The responsibilities associated with this mandate are as follows:

- Provide scientific advice to the Governance Committee on policy related to Registry operations.
- Select the module's data elements to be collected by the Registry.
- Review and approve annual and ad-hoc reports on trends, clinical effectiveness and epidemiological findings.
- Promote participation in the Registry by data holders.
- Promote use of Registry by research groups, academia, industry, and government.
- Review research proposals for scientific quality and completeness and provide opinion on their scientific value.
- Advise research groups on the availability of appropriate data elements in the Registry.
- Collaborate with research groups as appropriate.

Authority

The Topic Expert Group has the authority to select the topic's data elements collected by the Registry, and to discontinue or expand the collection of certain data elements, report on Registry findings, enforce data quality and integrity measures, accept or reject requests for data, and enter into collaborative arrangements with data users.

The Topic Expert Group may request from the Registry manager such information as it deems necessary and appropriate to fulfill its mandate.

Membership and Structure

Topic Expert Group members are appointed based on their clinical, research, and information analysis skills and expertise, or their experience as a patient with a bone and joint health condition.

The Topic Expert Group Chair is appointed by ABJHI. The Chair determines the number of members required by the Topic Expert Group to carry out its responsibilities. Members are nominated by the Chair and appointed by consensus of the Committee.

There is no limit to the term of the Topic Expert Group Chair. Other members are appointed for a term of one or two years and may be reappointed without limitation to the number of consecutive terms.

Independence

Members of the Alberta Bone and Joint Health Registry Topic Expert Group act in the interests of the Registry when competing interests arise.

Working Arrangement

- ABJHI will provide a non-voting member to perform secretarial duties, such as coordinating the Topic Expert Group's meetings, recording and distributing minutes of meetings, and supplying materials required by the Topic Expert Group to perform its function.
- Any Registry data placed before the Topic Expert Group is handled in compliance with protocols and procedures to protect the privacy and security of health information as set forth in the Privacy Impact Assessment for the *Alberta Bone and Joint Health Registry*, file # (To be submitted).
- Group members sign an Oath of Confidentiality describing their responsibility not to wrongfully divulge any of the information or records placed before them for Topic Expert Group business to any individual or party outside of the Topic Expert Group membership.
- Group decisions are by consensus and are recorded and provided to the Topic Expert Group members.
- The Topic Expert Group Chair sets the agenda for meetings and approves agenda packages before they are distributed.
- Attendance at meetings may be in person or via secure teleconference.
- The Chair and more than half the membership must be present to form a quorum.

Data Governance

The Governance Committee will guide ABJHI on appropriate uses of the Alberta Bone and Joint Health Registry for the purposes of research. ABJHI use of data must abide by the following:

- Health Information Act
- Affiliation agreements between ABJHI and custodians
- AHS Privacy Standard for non-identifying health information/ IPO-2013-0004
- AHS Data Access and Use for Health System Improvement Purposes (Secondary Use)
- Ethics approvals
- Terms provided in the patient consent forms

The Topic Expert Group will act in accordance with these requirements.

Duration and Frequency of Meetings

Meetings will not be more than four hours in duration except by consensus of Topic Expert Group members.

The Topic Expert Group will meet three times in the first year, then reduce to two meetings per year. Meetings may be added or cancelled at the discretion of the Chair.

Remuneration

Topic Expert Group members will be compensated for agreed out of pocket expenses. Fee for service members will receive a stipend according to the agreed rates based on meeting time.

Approved: _____

Date: _____

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