



**TERMS OF REFERENCE  
ALBERTA BONE AND JOINT HEALTH REGISTRY  
GOVERNANCE COMMITTEE**

**Background and Purpose**

The Alberta Bone and Joint Health Registry ('Registry') is an initiative of the Alberta Bone and Joint Health Institute (ABJHI). The Registry collects information on the health status of people with bone and joint conditions, the effectiveness of bone and joint interventions, and the performance of such interventions for the purposes of continuously improving clinical standards and patient outcomes. Data held in the Registry are a rich source of reliable information for advancing clinical practice, medical research and bone and joint device manufacturing.

The Alberta Bone and Joint Health Registry's Governance Committee oversees the operation and activities of the Registry to ensure it functions effectively and its integrity is maintained.

**Alberta Bone and Joint Health Registry Governance Committee Mandate**

The Alberta Bone and Joint Health Registry Governance Committee is mandated to oversee the functioning and progress of the Registry.

The responsibilities associated with this mandate include:

- Report annually to the ABJHI Board on the performance of the Registry with emphasis on where and how it is generating value
- Develop and implement policies for the effective operation of the Registry
- Ensure the information collected by the Registry is appropriate for continuously improving clinical standards and patient outcomes
- Monitor the Registry's work and progress
- Provide financial oversight of the Registry
- Provide Governance of other Registry committees and groups
- Establish ad-hoc committees as needed
- Establish informed consent standards and requirements.
- Establish data quality and integrity measures.
- Promote use of Registry by research groups, academia, industry, and government.

**Authority**

The Committee has the authority to develop and implement policies for the effective operation of the Registry. The Committee may request from the Registry manager such information as it deems necessary and appropriate to fulfill its mandate.

**Membership and Structure**

The Governance Committee comprises individuals with clinical, research, information analysis, and operations management expertise, or experience as a patient with a bone and joint condition.

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

The Governance Committee Chair and other members are appointed for a term of one or two years and may be reappointed without limitation to the number of consecutive terms.

The Governance Committee reports to the ABJHI Executive. Members will sign a 1- or 2-year formal membership agreement. Members should be willing to meet one or more of the following requirements:

- Patient with a bone and joint condition or family member
- Practicing clinician in bone and joint health
- Custodian of data
- Bone and joint health research experience
- Be willing to attend a maximum of four meetings per year

The Governance Committee is comprised of the following members:

- Two patient or family representatives
- Two University Researchers (1 each from UC & UA) with relevant bone and joint expertise
- One Executive representative from ABJHI
- Maximum of three clinicians with bone and joint health expertise
- One representative of the Bone and Joint Health Strategic Clinical Network (BJH SCN)
- One ABJHI employee providing administrative support (non-voting)

### **Independence**

Members of the Bone and Joint Health Registry Governance Committee 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 Committee's meetings, recording and distributing minutes of meetings, and supplying materials required by the Committee to perform its function.
- Any Registry data placed before the Committee 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).
- Committee members sign an Oath of Confidentiality describing their responsibility not to wrongfully divulge any of the information or records placed before them in the course of Committee business to any individual or party outside of the Committee membership.
- Committee decisions are by consensus and are recorded and provided to the Committee members.
- The Committee 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.

### **Quorum/Decision Making**

No decision is made without a quorum. The chairperson and 50% of members constitute a quorum. Decisions shall be made by the consensus of the Governance Committee.

Consensus is defined as:

*Members can live with the proposed position or decision, even though it may not be their preferred one, and thereby give their consent to proceed on the decision and to support it.*

### **Reporting**

The Governance Committee will report all relevant information and decisions to the Directors of Operations (Administrative and Technical) of ABJHI and the ABJHI Registry Project Manager. Members act independently and do not report on the business of the Governance Committee to any association, group, employer, authority, individual, or other body unless required by law.

### **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

### **Duration and Frequency of Meetings**

The Governance Committee will meet four times in the initial year and twice per year thereafter. The standard meeting duration is two hours but may be adjusted depending on the agenda. Meetings shall not exceed four hours and regular meetings are to be booked a minimum of two months in advance. Additional meetings may be called at the discretion of the Chair.

### **Remuneration**

Governance Committee 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: \_\_\_\_\_