

InSiGHT Variant Databases Governance Committee Terms of Reference

1. Purpose of Document

- 1.1. The purpose of this document is to describe in a way suitable for a wide readership the governance framework of the InSiGHT Variant Databases
 - 1.1.1. Provide a convenient reference for the use of Members, Directors and staff of the InSiGHT and the members of the committees that are established by the Board of Directors of the Company.
 - 1.1.2. Communicate the governance framework to others who have a legitimate interest.
- 1.2. This document may be released into the public domain.

2. Responsibilities of the InSiGHT Variant Databases Governance Committee

The committee will:

- 2.1. Ensure that governance, systems and processes are established and are sufficiently rigorous to monitor, report and respond to important issues in the operations of the InSiGHT Variant Databases.
 - 2.1.1. Receive, monitor and review any financial issues relevant to the database operations, bi-annually before passing on to InSiGHT Administrative secretary.
 - 2.1.2. Endorse reports from the curators that are submitted to Council.
 - 2.1.3. Oversee the currency of data on the InSiGHT Variant Databases, and their interpretation.
 - 2.1.4. Ensure that patient data available on the databases are rigorously anonymous.
- 2.2. Be alert to the ramifications, including medico-legal, of any misclassifications of pathogenicity assignment that emerge with access to new data relating to families whose variants are represented on the database.
- 2.3. Ensure that the organisational culture supports and promotes inquiry, continuous improvement, open disclosure of errors and effective, timely responses to problems.
- 2.4. Address ethical issues as they may arise, and call on ethical consultations where necessary.

- 2.5. Be responsible for ensuring the curators lead prudent financial management without impact on InSiGHT's resources unless approved by Council.
- 2.6. Determine relationships with other stakeholders through MOUs, including commercial interests, government interests and academic interests. The Governance Committee will endorse relationships with external stakeholders, including any MOUs and/or financial arrangements involving the databases, before passing them onto InSiGHT Council. Council will remain responsible for financial affairs, but be advised by the Chair of the Variants Database Governance Committee.
- 2.7. Determine from time to time additional genes that need curation through establishment of a locus specific database, and propose curators and Variant Interpretation subcommittees around such genes for approval by InSiGHT Council.
- 2.8. Advocate for the submission of variant and associated data to the InSiGHT Variant Databases from InSiGHT members and external organizations including government repositories (eg ClinVar) and other national sources.
- 2.9. Promote the public availability of the curated information contained in the InSiGHT databases.

3. Membership

Members of the committee shall be appointed by Council and shall consist of up to four members. In making the appointments, Council will take into account the views of existing Governance Committee members. Membership will include:

- 3.1. The Convenor shall be appointed by the Council, this will normally, but not necessarily, be an InSiGHT Councillor. The Convenor may be the chair, but in circumstances where the chair is not a Councillor, the Convenor should be a Councillor. This will allow continuity of governance function over Councils, but also allow appropriate expertise to chair the Variants Database Governance Committee. The Convenor, unless Chair or a member of the Variants Interpretation Committee, will have no other active role.
- 3.2. A Chair will be appointed by the Committee. The Chair will be an active health professional in the field of understanding DNA variation.
- 3.3. The term of Governance Committee members will be for two years with the option of re-appointment for a further two terms of two years.
- 3.4. A quorum shall be two members one of whom shall be the convenor.
- 3.5. Members of the Variant Databases Governance Committee must be InSiGHT members and be active in curation, management or



interpretation of DNA variation in genes relevant to gastrointestinal cancer.

- 3.6. Additional members may be co-opted from time to time and for a particular purpose. This will be at the discretion of the Convenor or Chair.
- 3.7. Each of the curators of the InSiGHT Variant Databases can be ad hoc non-voting attendees at Variant Databases Governance Committee meetings where their database is under discussion.

4. The InSiGHT Locus Specific Database Variant Interpretation Committee

- 4.1. There will be a single InSiGHT Variant Interpretation Committee (VIC). The InSiGHT VIC will be chaired or co-chaired by an InSiGHT member with expertise in variant interpretation. Chairs can be members of the Variant Databases Governance Committee.
- 4.2. Subcommittees with gene specific expertise will be established as part of this committee. Members of the VIC can be members of any number of subcommittees. Chairs of subcommittees will be appointed on the recommendation of the VIC Chair(s) by the Variant Databases Governance Committee.
- 4.3. There will be no limit on the number of members of the InSiGHT VIC or its subcommittees.

5. Key relationships

- 5.1. The Variant Databases Governance Committee is responsible to, and reports at least annually, to InSiGHT Council.
- 5.2. The Variant Databases Governance committee will work in close association with the InSiGHT Variant Interpretation Committee through the chairs of those committees and subcommittees.
- 5.3. The Variant Databases Governance Committee may from time to time be called upon to engage with managers of external databases with whom the InSiGHT databases interact. This might include the NCBI ClinVar database and its curation arm ClinGen.
- 5.4. Any commercial arrangements involving the InSiGHT Variant Databases must be approved by the Variant Databases Governance Committee, who will further refer such matters to InSiGHT Council.

6. Operating principles

- 6.1. The Convenor or Database Curator will call meetings in consultation with the Chair.
- 6.2. The notification and agenda for a meeting will be circulated to members at least five working days prior to the meeting.



- 6.3. The committee may obtain external resources as required to assist with its work.
- 6.4. The committee shall report to Council after each meeting or as requested by Council. Committee meetings shall be minuted, a copy to be tabled at the following Council meeting.
- 6.5. Changes in membership, roles or responsibilities shall be determined by the Council.
- 6.6. The committee shall meet at least bi-annually.
- 6.7. Meetings are open for any member of the InSiGHT Council to attend.

7. Authority

- The Variant Databases Governance Committee shall have no executive powers with regard to its recommendations.

Approved by the InSiGHT Variants Databases Governance Committee

Accepted by Council Jan 2018

Date for review 1 Jan 2021

