Committee: CCMG Responsibility to Recontact for Clinical Genetic Testing Ad Hoc Working Group
Document: Terms of Reference (ToR)
Dates:  Prepared by the Committee, February 2021
Approved by the Board of Directors, February 24, 2021

Brief Background for Formation of Working Group:
The Clinical Responsibility to Recontact for Clinical Genetic Testing working group was initially formed in
2017 from some of the existing members of the Education, Ethics and Public Policy (E2P2) Committee. The
Board subsequently approved the addition of 2 more members: (1) Ma’n Zawati, Assistant Professor and
Executive Director, of the Centre of Genomics and Policy (CGP), who became the legal
representative on the working group and (2) Yvonne Bombard, associate affiliate CCMG member who
was instrumental in writing the “Research Responsibility to Recontact” ASHG statement. The initial
focus was to formulate a recommendation regarding the Responsibility to Recontact in a Canadian context. The working group was paused at the end of 2017 since we were aware that the Research Responsibility to Recontact working group was planning to publish their statement. The working group was restarted following the publication of the Research Responsibility to Recontact with its first meeting on November 13, 2019. The focus was changed to the Responsibility to Recontact for Clinical Genetic Testing.

Mandate
The purpose of this CCMG Ad hoc Working Group is to develop and publish a document (yet to be
decided as either a Clinical Practice Advisory Document (CPAD) or Clinical Practice Guideline) to promote
discussion and to document suggestions/recommendations regarding the clinical responsibility to
recontact for clinical genetic testing.

Timeline
The working group has had 7 meetings (Dec 2017, November 13, 2019, Feb 5, 2020, April 1, 2020, July
17, 2020, September 21, 2020 and January 15, 2021). The intention is to continue having meetings every
3 months until a document can be produced for approval by the CCMG Board of Directors. A general
outline of planned topics for discussion draft was started in Fall 2020. The first sessions have been
primarily brainstorming on the type of document, the scope of the issues, working group composition
and plans to address literature review.

Membership:
The membership should include representation across Canada in the following categories:

- Laboratory geneticists
- Clinical/Medical Geneticists
- Legal representation and Ethics representation
• One Genetic counsellor
• Patient input – Two active patient members with one member representing the interests of their child with a genetic condition and an adult member who has a genetic condition. We will also solicit patient group input upon review of the document.

Current Membership:
Ron Agatep – Laboratory Geneticist, CCMG
Yvonne Bombard – Genomics Health Services Researcher, Health Policy, CCMG associate/affiliate member, Primary author on ASHG research statement
Lauren Chad – Medical Geneticist, Bioethics, E2P2, CCMG
Elaine Goh – Medical Geneticist, E2P2 Chair, CCMG
Anne-Marie Laberge – Medical Geneticist, E2P2, CCMG, GE3LS researcher
Melanie Lacaria – Laboratory Geneticist, E2P2, CCMG
Tanya Nelson – Laboratory Geneticist, CCMG representative on ASHG statement, CCMG
Julie Richer – Medical Geneticist, Started working group, CCMG representative on ASHG statement, CCMG
Mary Ann Thomas – Laboratory / Medical Geneticist, Board member for E2P2 since June 2020, CCMG
Ma’n Zawati – Law, Centre of Genomics and Policy, McGill University

Patient representatives and new genetic counsellor member - pending

Previous member: Linlea Armstrong, Medical Geneticist, Board member for E2P2 until June 2020.
Victoria Siu, Medical Geneticist, CCMG contributed to the working group and resigned September 2020.
Shannon Ryan, Genetic Counsellor, CAGC contributed to the working group until December 2020.

Confidentiality
Matters discussed at meetings and teleconferences are confidential and may not be disclosed to others. Exclusion to this includes information that was previously published or in the public domain, or information which was already known to the member and was not acquired by the member directly or indirectly from the committee.

Conflict of Interest
Members should disclose any known or perceived conflicts of interest. When the main goal of the working group is development of educational materials, guidelines or recommendations on a specific topic, simultaneous participation in similar activities led by external organizations might be perceived as a conflict of interest. If such situations arise, the member should discuss this with the chair(s) and BoD representative, who could seek the advice of the BoD on that matter.

Appointment and term of chair
The chair of the working group is the current chair of E2P2 (Julie Richer was previous chair of E2P2 and the working group in 2017).

Conduct of Meetings
• The chair will convene regular zoom meetings of the Ad Hoc Working Group, with approximately one meeting held every three months or more frequently if required.
• Quorum for decisions will be at least 50% of Working Group members
• Draft minutes of all meetings will be prepared and circulated to the Working group members for comment, ideally within 10 working days of the meeting.
• All meeting minutes will be made available to CCMG Board of Directors via the Board of Directors Representative.

Reporting
The chair will report to the CCMG Board of Directors via the Board representative for quarterly updates. The chair will submit to the CCMG Board of Directors documents at two stages of the writing process, i.e.1) A draft outline with bullet points outlining major points the authors (Working Group members) anticipate addressing, and 2) a complete version of the manuscript. These documents will be submitted to the CCMG Board of Directors to seek their feedback and to obtain feedback from the following CCMG committees: E2P2, Clinical Practice, and Laboratory Practice. The document will also be circulated to patient groups for their input. The final manuscript must be submitted to BoD for approval.