Committee: CCMG Reproductive Carrier Screening Ad Hoc Working Group  
Document: Terms of Reference (ToR)  
Dates: Prepared by the Committee, May 2022  
       Approved by the Board of Directors, May 24, 2022

Brief Background for Formation of Working Group:  
In 2016, the SOGC and CCMG published a joint statement entitled “Joint SOGC-CCMG Opinion for Reproductive Genetic Carrier Screening: An Update for all Canadian Providers of Maternity and Reproductive Healthcare in the Era of Direct-to-Consumer testing”. Since its initial publication, reproductive carrier screening has seen an increase in uptake and expansion in availability of testing in Canada. Concurrently, advances in therapeutic options for genetic diseases, such as spinal muscular atrophy, have changed the discussion about preconception and prenatal testing options for such disorders. A recent review of this document by the SOGC has determined that given the above changes, the committee opinion requires an update. Therefore, the 2016 document has been retired. The SOGC has approached the CCMG through the Clinical Practice committee, as previously reviewed with the board, to lead the creation of an updated document. The Clinical Practice Committee discussed the need to create an Ad hoc working group of interested committee members to review the evidence and author a revised publication as it relates to reproductive carrier screening in Canada. Concurrently, the Clinical Practice committee was asked to review the CCMG statement on cystic fibrosis testing. While the majority of this work will be done through the lab practice committee as it deals more directly with the labs, the clinical aspects of preconception testing overlaps with the content of the reproductive carrier screening document and will be addressed in this document as well.

Mandate  
The purpose of this CCMG Ad hoc Working Group is to develop, publish, and disseminate an expert opinion on the best use of reproductive carrier screening technologies in the Canadian context.

Timeline  
Initial Subcommittee planning meeting - April 2022  
Submission of ToR document for board approval – May 2022  
Monthly meetings starting May 2022  
Completion of draft document- October 2022
Submission to CCMG board and Circulation to CCMG committees – Nov 2022
Circulation to CCMG membership Dec 2022/Jan 2023
Submit for publication Feb 2023.

Membership:
1. This group is primarily made as a subcommittee of the CCMG Clinical Practice committee and shall include 4-6 members of the clinical practice committee including a genetic counsellor representative (already on the Clinical Practice committee).
2. One representative from the CCMG lab practice committee
3. Other ad hoc CCMG members may be added based on expertise determined during the writing of the document.
4. 1-2 Members of the SOGC Genetics committee as decided on by that committee.
5. We would like to request the service of a Medical Writer.

Confidentiality
Matters discussed at meetings and teleconferences are confidential and may not be disclosed to others. Exclusion to this is includes information that was previously published or in the public domain, or it is information 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, participation in similar activities (during the time frame of the Working Group activities) on the same topic led by external organizations might be perceived as a conflict of interest. If such situations arise the member of working group should discuss this with the chair(s) and BoD representative, which if required could seek the advice of the BoD on that matter.

Appointment and term of chair
Two co-chairs will be selected from the membership of the Ad Hoc Working group for the duration of the existence of the Working Group
Conduct of Meetings

- The co-chairs will convene regular zoom meetings of the Ad Hoc Working Group, with approximately one meeting held each month or more frequent 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 co-chairs will report to the CCMG Board of Directors via the Board representative for monthly updates.

After completion of the manuscript, it will be reviewed by the full Clinical Practice Committee. It will then be submitted to CCMG Board of Directors to seek the feedback from the following CCMG committees:

- E2P2 Lab Practice (may depend on content of the final document if this is required).

The document will then be circulated to the full CCMG membership for comment.

We request that the document be sent to the CAGC for endorsement. The SOGC unfortunately does not currently offer endorsement of documents, however, should that change, endorsement by the SOGC would be sought.

The final manuscript will be submitted to BoD for approval.

We hope to publish this document in a journal available to those doing prenatal and preconception care: examples include the JOGC, CMAJ, Canadian Family Physician. Publication fees are in the range of ~$3000 for most of these journals. Companion articles, such as letters to the editor, may be written to further promote the document as needed if all prenatal care providers cannot be reached with a single publication.