



Canadian Association of Genetic Counsellors

The Canadian experience of
alternative models of service
delivery: Practical guidance for
genetic counsellors

Introduction

Increased awareness, testing options and demand for genetic counselling in Canada has led to compromised accessibility and long wait times for patients in many genetic clinics. This situation has necessitated the development and implementation of alternative models of genetic counselling deviating from the traditional model whereby a genetic counsellor meets with a patient one-on-one for pre-test counselling and then again for post-test counselling. Novel models have re-imagined the standard paradigm for both pre-test and post-test genetic counselling to ultimately improve access for patients.

In December 2020, the Canadian Association of Genetic Counsellors (CAGC) Alternative Models of Genetic Counselling Community of Practice group formed to promote a national collaboration for sharing knowledge regarding the creation, delivery and evaluation of alternative models of genetic counselling care. Over the following seventeen months, the group met to share and discuss the current landscape of genetic counselling approaches nationwide. The group then prepared descriptions for each model, with the goal of creating a comprehensive document which could be shared with the Canadian genetic counselling community.

The purpose of this document is to summarize options for next generation genetic counselling in Canada and provide practical guidance for the CAGC membership should counsellors across the country wish to consider adopting novel models of care in their own regions. The various models detailed in this document each describe a summary of learnings, as well as tips for getting started, accessibility and equity considerations, cautions and some Canadian success stories. A separate chapter with information regarding the evaluation of genetic counselling service delivery models is also included, as assessment of these models may be beneficial for research or justification purposes. Contact information for centres, who have used or are currently using such models, is available should communication with these genetic counsellors be valuable. It is hoped that this information may inspire and assist Canadian genetic counsellors who wish to develop alternative models of service delivery in their own centres.

The alternative models which are described in the most recent version of this document or will be included in a future draft include (in alphabetical order):

- 1) Chat bots: Chatbots are tools that use artificial intelligence and can simulate conversations with patients to provide them information and respond to questions. *This section is currently in progress and will be added to the next draft.*
- 2) Decision Aids: These refer to tools or resources that are designed to assist patients and healthcare providers in making informed decisions about their health care and treatment options, by providing evidence-based information and values clarification about available options, benefits, risks and outcomes.
- 3) Genetic counselling assistants: GCAs and genetic assistants are non-clerical staff who are generally not responsible for direct clinical care but primarily perform 'behind the scenes' coordination and administrative tasks traditionally assigned to genetic counsellors. This document is focused on support for genetic counsellors; as such, we have used the term 'genetic counselling assistants'.
- 4) Group genetic counselling: This is generally defined as a genetic counsellor providing in person pre-test counselling (or virtually) to multiple patients at once, with or without a follow-up one-on-one session(s).

- 5) Mainstreaming: In the mainstreaming model, non-genetics clinicians provide pre-test information to their patients and obtain consent for genetic testing, which eliminates patient wait-times for pre-test genetic counselling in the genetics clinic.
- 6) Patient portals: In the context of genetic counselling, digital tools, known as patient portals, have been developed and utilized for various purposes such as documenting pedigree information, performing risk assessments, providing education and returning results.
- 7) Telehealth genetic counselling: This includes individualized virtual genetic counselling either by telephone or by videoconference.
- 8) Videos: Patient education videos can be useful tools to address relevant genetics concepts both pre-test and/or post-test.
- 9) Webinars: A webinar is a live presentation that takes place virtually, allowing participants in different locations to see and hear the presenter, to ask questions and, possibly, to answer polls.

If information on a specific model is needed, it is suggested to go directly to that section.

It is important to note that since the establishment of the profession of genetic counsellors, a huge evolution has occurred in the training, practice and employment milieu of genetic counsellors. Rapid advancements in the field of medical genetics itself have pushed this evolution and continue to propel further change and adaptation (Biesecker, 2020; McCuaig et al., 2018). Genetic counsellors have already come a long way and should well expect that their field of practice will continue to progress at the speed of light. There are numerous articles and other resources available regarding alternative models of genetic counselling service delivery, including the Digital Tools for Genetic Professionals* and these resources are fully expected to proliferate over time. The Alternative Models of Genetic Counselling Community of Practice group prepared this document in 2024, knowing that the practice of genetic counsellors will continue to evolve and that other innovative models of genetic counselling service delivery may well be developed in the future. As such, the goal will be to revise and update this document, approximately every 2-3 years.

References

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*National Society of Genetic Counselors, Health IT SIG, Digital Tools for Genetic Professionals

https://www.nsgc.org/Portals/0/NSGC%20Digital%20Tools%20for%20Genetics%20Professionals%20Version%202023_1%20%5BFINAL%5D.pdf

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Executive summary

A perceived need to better understand the use of alternative models of genetic counselling service delivery in Canada led the Canadian Association of Genetic Counsellors (CAGC) to create a new Community of Practice (CoP) group in 2020. The aim of the CoP was to promote a national collaboration for sharing knowledge regarding the creation, delivery and evaluation of alternative models of genetic counselling care. The document, developed on the basis of the work of this group: The Canadian experience of alternative models of service delivery: Practical guidance for genetic counsellors, is an openly available resource as a reference on the subject for CAGC members.

Increased awareness, testing options and demand for genetic counselling (GC), along with the limited numbers of genetic counsellors has led to compromised accessibility and long wait times for patients in many genetic clinics. This situation has led to the development and implementation of alternative models of genetic counselling deviating from the traditional model whereby a genetic counsellor meets with a patient one-on-one for pre-test counselling and then again for post-test counselling. The implementation of innovative models of GC service delivery may increase service efficiency, improve patient access to services and sustain the practice of genetic counsellors.

The alternative models which are described in the 2024 version of this document or will be included in a near future draft include (in alphabetical order):

- 1) Chat bots: A genetic counseling chatbot is an artificial intelligence computer program which can simulate human conversation with a patient with the goal of providing information and responding to questions.
- 2) Decision Aids: These refer to tools or resources that are designed to assist patients and healthcare providers in making informed decisions about their health care and treatment options, by providing evidence-based information and values clarification about available options, benefits, risks and outcomes.
- 3) Genetic counselling assistants: GCAs are non-clerical staff who are generally not responsible for direct clinical care but primarily perform 'behind the scenes' coordination and administrative tasks traditionally assigned to genetic counsellors.
- 4) Group genetic counselling: This is generally defined as a genetic counsellor providing in person pre-test counselling to multiple patients at once, with or without a follow-up one-on-one session(s).
- 5) Mainstreaming: In the mainstreaming model, non-genetics clinicians provide pre-test information to their patients and obtain consent for genetic testing, which eliminates patient wait-times for pre-test genetic counselling in the genetics clinic. Post-test genetic services are built into this model, but may differ based on individual jurisdictions or contexts.
- 6) Patient portals: In the context of genetic counselling, patient portals are digital tools that have been developed and utilized for various purposes such as documenting pedigree information, performing risk assessments and providing education.
- 7) Telehealth genetic counselling: This includes individualized virtual genetic counselling either by telephone or by videoconference.
- 8) Videos: Patient education videos can be useful tools to address relevant genetics concepts both pre-test and/or post-test.
- 9) Webinars: A webinar is a live presentation that takes place virtually, allowing participants in different locations to see and hear the presenter, to ask questions and, possibly, to answer polls.

The detailed descriptions of the alternate models of genetic counselling service delivery in this document include, for each model, a summary of learnings, tips for getting started, points regarding accessibility and equity, cautions to consider and some accounts of Canadian success stories. A separate chapter with information regarding the evaluation of genetic counselling service delivery models is also included, as assessment of these models may be beneficial for research or justification purposes, or future revisions to the model. The goal in creating this document is to provide practical guidance for the CAGC membership should counsellors in any region across Canada wish to consider adopting novel models of care for their own practice.

Any change in healthcare practice comes hand-in-hand with challenges and undertakings in implementing new models of genetic counselling service delivery are no exception. Some noted barriers to developing novel models of care include time constraints, a lack of administrative, institutional or physician support and issues regarding funding and reimbursement for services. Approaches to new service delivery model selection and implementation are impacted by different institutional needs, available resources, and specific populations. Support from both institutional and clinic leadership, as well as collaboration with stakeholders (including patient partners), are all required to move forward constructively in implementing new models of service delivery. It is, however, reassuring to note the wide range and growing use of innovative models in Canadian genetic counselling services, despite the challenges involved.

Genetic counsellors are still a relatively young profession and, ever since their initial integration into health care teams, continual progression is underway in their training, practice and employment milieus. The rapid advancements in the field of medical genetics itself have pushed this evolution and will continue to propel further change and adaptation. It is not surprising that many Canadian genetic counsellors have already embraced new models of service delivery. The Alternative Models of Genetic Counselling Community of Practice group prepared the initial version of this document in 2024, knowing that the practice of genetic counsellors will continue to evolve and that other innovative models of genetic counselling service delivery may well be developed in the future. A review of these models, as well as newer developed ones, is planned in time, so that this document remains current and useful for CAGC members.