Ontario Health
Cancer Care Ontario

Enhancing Clinical Cancer Genetic Service Delivery in Ontario

Recommendations for a New Model of Care

November 2020

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Executive Summary

Introduction

In September 2019, Cancer Care Ontario, a business unit of Ontario Health, formed a working group to develop recommendations for an enhanced model of care for clinical cancer genetic services. The recommendations in this report were formed through the working group, which used the best available evidence, expert knowledge, and patient and provider engagement to meet the following objectives:

- Ensure timely access to high-quality care in appropriate settings as close to home as possible;
- Support collaboration among providers, increase capacity and maximize efficiencies in care delivery; and
- Optimize health system resource use.

Enhancing the current model of care was a priority identified in the 2018 *Recommendation Report for Ontario's Clinical Genetic Services* as a way to increase the efficiency of the health care workforce, integrate services and increase access to high-quality clinical cancer genetic services across Ontario.

The 2018 report showed that the number of clinicians with expertise in genetics (medical geneticists, oncologists and genetic counsellors) working in cancer genetics clinics in Ontario has remained fairly constant, despite the marked increase in cancer genetic counselling referrals to clinics over the past 10 years.[1] This increase in referrals can be attributed to multiple factors and notably coincides with the rising demand for genetic testing as a result of the development of new tests, the development of personalized cancer therapies and increased public awareness of hereditary cancer.

It was estimated in the report that Ontario needs an additional 35 genetic counsellor full-time equivalents to address long wait times and the increasing demand for services. Under the current care delivery model, there are not enough resources to meet this demand.

Background

People with or without cancer who are identified as being at risk for a hereditary cancer syndrome are eligible for genetic services. Genetic services help individuals and families make decisions about their health and learn about ways to help lower their risk for cancer (e.g., risk-reducing screening, treatment or surgery).

The traditional approach to accessing genetic services involves referral to a genetics clinic, with services provided over multiple, in-person visits. Alternatives to this traditional approach are gaining popularity because they address ways to improve process and provider efficiencies and increase access to services. The following recommendations build on these traditional and alternate models in an effort to increase provider capacity and access to high-quality clinical cancer genetic services in Ontario.

Recommendations

The recommendations are organized into three sections. The first section focuses on the interdisciplinary team, the next section follows the episode of care and the final section outlines system-level recommendations for the province.

The Interdisciplinary Team Recommendations

1. Optimize the roles and functioning of the clinical cancer genetics team

1.1. The interdisciplinary clinical cancer genetics team should include, at minimum, a physician lead, genetic counsellor, genetic assistant, and clerk, each working to their optimal scope of practice.
1.2. Team members should be located in close proximity or be linked through technologies to facilitate sharing cases, sharing personal health information, and inter-professional communication and collaboration.

Episode of Care Recommendations

2. Standardize referral and triage processes

2.1. Referrals to clinical cancer genetics services should be submitted and received electronically.
2.2. Referrals should be screened, triaged and prioritized using standardized processes.

3. Optimize workflow processes to streamline case preparation

3.1. Clerks, in partnership with genetic assistants, should support case preparation by collecting all required information.
3.2. Information to help people prepare for genetic counselling (pre-appointment video, information package) should be distributed in advance of the appointment, with a genetic assistant available to help answer pre-appointment inquiries.
3.3. Technology should be leveraged to streamline case preparation tasks, such as collecting health history data, automating risk modelling and generating the pedigree.

4. Improve access to genetic counselling through alternate settings

4.1. Where appropriate, people should be offered a genetic counselling appointment by telephone or videoconference.
4.2. Group counselling visits should be used for patient populations that are similar and have a high-volume of referral.

5. Streamline access to germline genetic testing for eligible patients

5.1. Genetic counsellors should order genetic testing for eligible patients according to institution-specific policy.
5.2. When appropriate, cancer team and other specialist teams (e.g., oncologist, surgeon) should work in conjunction with the clinical cancer genetics team to facilitate expedited access to genetic testing for eligible patients.
5.3. The genetic counsellor or physician lead should lead all results interpretation and disclosure for the tests they order, and the tests ordered by cancer team and other specialist teams.
5.4. Unless otherwise indicated by the person who received genetic testing, test results should be disclosed by phone and made available to them through a secure online tool.

6. Work with providers to ensure smooth transitions for follow-up care

6.1. The genetic counsellor or physician lead should create a clinical cancer genetics follow-up care plan for their patients.
6.2. The genetic counsellor or physician lead should connect their patients to the most responsible provider to manage clinical cancer genetics follow-up care.

7. Provide equitable access to information, navigation and support

7.1. Patients receiving genetic counselling should have access to their genetic personal health information, appointment information and support resources through a secure patient portal.
7.2. Patient navigation throughout the episode of care is the responsibility of the clinical cancer genetics team and should be provided by the most appropriate team member (e.g., physician lead, genetic counsellor etc.).

System-Level Recommendations

8. Establish provincial oversight for clinical cancer genetics services

8.1. Develop a comprehensive and sustainable funding plan for clinical cancer genetic services delivery that includes operational and volume-based allocations.

8.2. Implement standardized resources and tools for providers and their patients that help ensure high-quality care delivery and patient management.

8.2.1. Develop, endorse and share standardized clinical guidance for cancer genetic services across the province.

8.2.2. Referral should be provincially or regionally coordinated and supported by a provincially standardized electronic referral platform.

8.2.3. Develop, endorse and share standardized genetics education resources across the province.

8.2.4. Develop, endorse and share standardized training and resources for providers across the province.

8.3. Integrate information management/information technology resources and electronic tools to facilitate secure sharing and receiving of personal and family health data, risk modelling and pedigrees and facilitate efficient case review.

8.4. Develop a provincial genetic testing results registry or database to support accurate and efficient clinical decision-making and surveillance.

Implementation Considerations

Successful implementation of this enhanced model of care will require a phased multi-year approach and mobilization of resources at local, regional and provincial levels. Short-term goals could focus on recommendations that require little financial investment to realize improvement. Specifically, immediate action could be taken to improve efficiency and capacity through:

- standardizing processes (Recommendations 2.2, 3.3, 5.1, 5.3, 6.1, 7.2, 8.2);
- optimizing scope of practice through task-shifting or by investing in administrative support (Recommendations 1.1, 3.1, 3.2, 4.1, 4.2); and
- using existing technology, such eConsult, the Ontario Telemedicine Network and others that are provincially available (Recommendations 1.2, 4.1, 8.2).

Although local agreement is required to move forward on the recommendations, provincial-level oversight should also be in place. Through its partnerships with the Regional Cancer Programs and the five transitional health regions, Ontario Health is well-positioned to help coordinate and implement the recommendations at the clinic level, align priorities to Ontario's Digital Health Strategy, and lead the planning and prioritization of longer-term initiatives.

Introduction

In 2018, Cancer Care Ontario, now a business unit of Ontario Health, released the *Recommendation Report for Ontario's Clinical Genetic Services*.[1] This report outlined the need to increase access to clinical cancer genetic services across Ontario, including the growing demand for hereditary cancer testing,[a] shortage of genetic counsellors across the province and subsequent long wait times for genetic counselling (Figures 1 and 2).

The number of clinicians specializing in genetics (e.g., medical geneticists, oncologists and genetic counsellors) and working in cancer genetics clinics in Ontario has remained mostly unchanged, despite the marked increase in cancer genetic counselling referrals to clinics over the past 10 years.[1] This increase in referrals can be attributed to multiple factors and notably coincides with the rising demand for genetic testing as a result of the addition of new tests, the development of personalized cancer therapies and increased public awareness of hereditary cancer.

A review of cancer genetic counselling wait times and referral volumes showed increasing referrals and long wait times. Under the current funding and care delivery model, there are insufficient resources in the system to meet the growing demand for clinical cancer genetic services.

Figure 1: Key Findings from the 2018 *Recommendation Report for Ontario's Clinical Genetic Services*

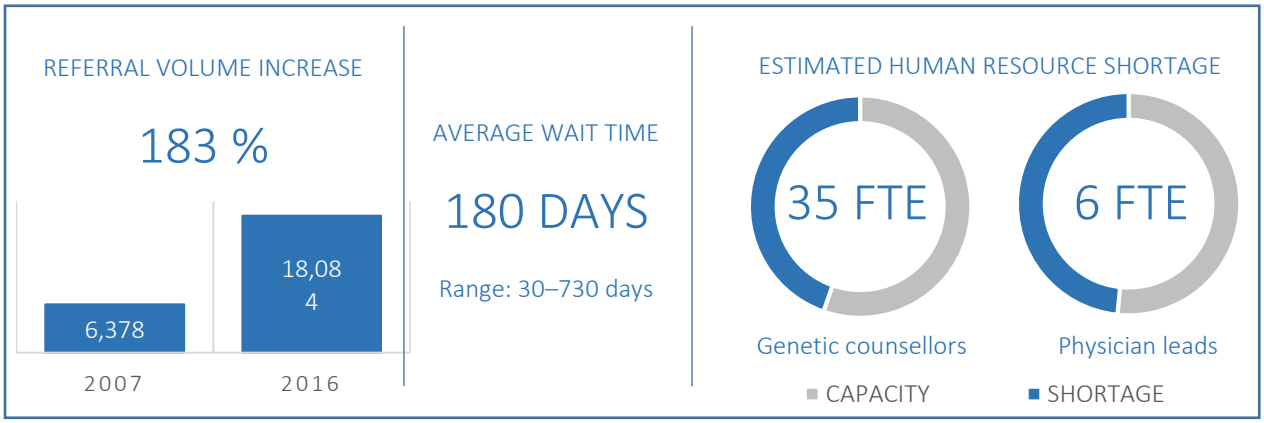
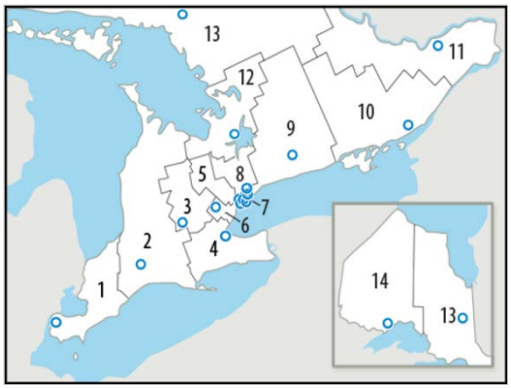


Figure 2: Ontario Genetics Clinics



Ontario Genetics Clinics	2018	2020
Cancer and General Genetics Clinic	11	11
Cancer and General Genetics Clinic: Northern Regional Genetics Program (NRGP)	5	3
Cancer Specialized Genetics Clinic	9	9
Specialized Genetics Clinic (no cancer)	4	4
General Genetics Clinic (no caner)	2	2
	31	29

[a] Hereditary cancer testing is the practice of testing for variants in genes associated with hereditary cancer

To address the needs of people in Ontario who are at risk for or who have a hereditary cancer syndrome, Ontario Health convened a working group to develop a recommended model of care that will increase capacity, access and quality of clinical cancer genetics services. A "model of care" is defined as the configuration, organization and delivery of health care services for an individual or group of people.[2]

The objectives for the recommended model of care are to:

- ensure timely access to high-quality care in appropriate settings as close to home as possible;
- encourage collaboration among providers, increase capacity and maximize efficiencies in care delivery; and
- optimize health system resource use.

Background

Approximately five to ten percent of cancer is hereditary, resulting from a gene mutation (pathogenic or likely pathogenic variant) that is inherited from a biological parent (e.g., BRCA1, BRCA2 in hereditary breast and ovarian cancer).[3] Genetic counselling is the process of helping people understand and adapt to the medical, psychological and familial impacts of these genetic contributions to disease.[4]

The clinicians who provide cancer genetic counselling are experts in the field of hereditary cancer and perform the following functions:

- conduct formal assessments of cancer risk;
- provide genetic counselling;
- facilitate access to genetic testing,[b] if appropriate, and interpret results in the context of hereditary cancer;
- make medical recommendations for disease prevention, early detection and surveillance; and
- transition care to other providers to ensure comprehensive genetics care for people with complex health issues or people discharged from genetics to receive treatment, surveillance and follow-up care.[4]

People who are eligible for genetic services are identified based on risk factors for a hereditary cancer syndrome found in their personal or family history. Traditionally, access to genetic services begins with a referral to a genetics clinic and services are provided over multiple, in-person visits. Eligible people are identified based on risk factors for a hereditary cancer syndrome found in their personal or family history.

Alternatives to traditional in-person visits have been explored globally and occur in pockets across Ontario. These alternatives include telephone visits, videoconferencing, group counselling and oncology-based genetic testing known as "mainstreaming." Mainstreaming is the process of offering germline genetic testing (i.e., a test to see if someone has a gene mutation that is known to increase the risk of developing health problems) to eligible patients in a cancer clinic through the most responsible provider.[5] Mainstreaming has emerged as a way to provide access to germline testing for specific populations. It eliminates upfront (pre-test) referrals to genetics clinics and initiates testing at an existing oncology appointment.[6,7]

The recommendations in this report build on these alternate models, while acknowledging that some people will still need a more traditional approach to genetics care. These recommendations are grounded in the idea that clinical cancer genetics care should ultimately be led by a team of genetics

[b] "Genetic testing is a medical test that looks at a sample of the patient's DNA for changes in chromosomes, genes or proteins that are linked to cancer" http://www.cancer.ca/en/cancer-information/cancer-101/what-is-cancer/genes-and-cancer/genetic-testing/?region=sk#ixzz6F5nfQCyP

experts. How, when and where that leadership takes place may vary for each interdisciplinary team (i.e., through direct care or in collaboration with other health care providers) and will rely on system-level oversight, collaboration and supporting technologies.

Approach

The Clinical Cancer Genetic Services Model of Care Recommendations were developed based on a combination of best available evidence and consultations with clinical providers, system administrators and people who have received genetics counselling.

A working group made up of stakeholders from across the province drove the development of the recommendations in this report. The working group (see Appendix A) included patient and family advisors, clinicians and Cancer Care Ontario (before the transition to Ontario Health) staff. The working group reviewed elements of service delivery models derived from scientific and grey literature, as well as input from people who have used genetic services and/or their caregivers solicited through an in-person focus group (see Appendix B). The working group discussed the current state of clinical cancer genetic services across Ontario, reflecting on the evidence and their own experience. The working group reviewed, discussed and provided written feedback on detailed tasks, providers and settings of care, which were categorized using the clinical cancer genetics services episode of care listed in Figure 3.

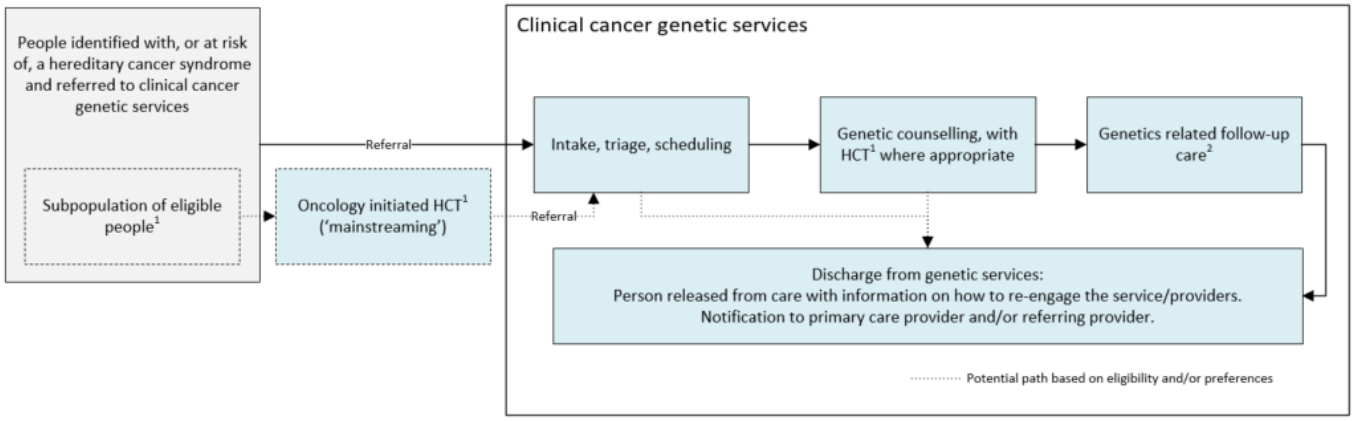
Scope

The Clinical Cancer Genetic Services Model of Care Recommendations focus on the activities and processes led by the clinical cancer genetics team, from the time a referral is received for cancer genetic services, to the time someone is discharged. The eligible population includes people with or without cancer who have or who are considered at-risk for a hereditary cancer syndrome. At a high level, Figure 3 describes the clinical cancer genetics services episode of care, with the blue boxes indicating the in-scope components for these recommendations.

The following elements are out of scope for the recommended model of care:

- referral processes from the perspective of the referring provider;
- technical or laboratory processes associated with hereditary cancer testing (i.e., the practice of testing for variants in genes associated with hereditary cancer syndromes);
- developing clinical practice guidelines or eligibility criteria; and
- all referrals for an indication outside of cancer genetics.

Figure 3: Clinical cancer genetics services episode of care



[1] For a select group of people with a personal history of cancer, hereditary cancer testing (HCT) may be initiated in an oncology setting prior to referral to genetic services. Oncology initiated genetic testing (or "mainstreaming") is the process of expediting access to HCT, involving both genetics and oncology services.

[2] Genetics related follow-up care may include: risk assessment, results disclosure, follow-up plan, and discussing risks for blood relatives

Recommendations

The following recommendations provide a framework for standardizing the organization and delivery of clinical cancer genetic services, and highlight key considerations for successful implementation in Ontario. The recommendations target health system planners, administrators, providers, and other individuals and organizations involved in the planning and delivery of cancer genetic services.

The recommendations are organized into three sections:

- The interdisciplinary team;
- The episode of care; and
- System-level recommendations for the province

A high-level diagram of the enhanced model of care based on these recommendations can be found in Appendix C. The recommendations include short- and long-term goals, and highlight key implementation considerations that acknowledge the various states of readiness that exist across genetics clinics in the province. While a number of these recommendations focus on the individual clinic or site, system-level oversight and investment are required to achieve equitable and sustainable cancer genetics services across the province.

The Interdisciplinary Team

1. Optimize the roles and functioning of the clinical cancer genetics team

Clinical cancer genetic services should be delivered by an interdisciplinary team of providers to ensure comprehensive and coordinated cancer genetic services that meet service user needs throughout the episode of care. An interdisciplinary team approach involves health professionals from different disciplines collaborating to deliver care, make decisions and share responsibilities. It also means including genetic service users in all decision-making.

1.1. The interdisciplinary clinical cancer genetics team should comprise, at minimum, a physician lead, genetic counsellor, genetic assistant, and clerk, each working to their optimal scope of practice.

Successful implementation of the interdisciplinary team approach requires clear definitions of each team member's responsibilities, and an understanding of their shared roles and responsibilities within the team. A high-level overview of the clinical cancer genetics team is provided in Table 1, with detailed roles and responsibilities described in Appendix D. Based on service user need and complexity, the clinical cancer genetics team may consult with other multidisciplinary providers to deliver the best possible care. These other multidisciplinary providers comprise the extended team (see Appendix D).

Table 1: Overview of the clinical cancer genetics team

Clinical Cancer Genetics Team Member	High-Level Role	Provider Type
Physician lead	• Provides clinical advice and leadership* to genetic counsellors • Cares for patients and provides consultations • Delivers education and guidance to people receiving genetic testing, their families and providers • Provides care management for specific populations • Creates clinical process guidelines and policies for the clinic • Orders and communicates genetic test results	Medical geneticist, oncologist or physician with experience and expertise in clinical cancer genetics
Genetic counsellor	• Advises genetic and administrative staff • Cares for patients and provides consultations • Delivers education and guidance to people receiving genetic testing, their families, providers and the public • Orders and communicates genetic test results with physician lead support, if needed	Genetic counsellor
Genetic assistant **	• Assists physician leads and genetic counsellors with clinical and administrative tasks	Genetic counsellor assistant, genetic assistant
Clerk	• Leads administrative tasks and provides operations support, such as scheduling, referral processing and managing patient inquires	Clerk, administrative assistant

* The breadth and scope of leadership will depend on local factors, including competencies and experience of the genetic counsellors, and clinic-specific policies and practices.
** This new, yet essential, role has not been provincially standardized. However, standardization is not a requirement for implementation. Please refer to Appendix D for the role description and to Appendix E for key activities of this role.

Ensuring that all providers can work to their optimal scope of practice is a priority given the high demand for genetic counselling services, present workforce shortages, and the evolving complexity of genetic testing and results interpretation.[8,9,10] Optimizing scope of practice on a team involves identifying the competencies of all team members to help determine the most effective composition of roles. This optimization includes the process of task-shifting or delegating tasks from a more costly health care resource to a less expensive health care resource, which results in the most appropriate use of the unique skills of each health care professional.

Appendix E provides a detailed list of activities performed by the clinical cancer genetics team across the episode of care, and outlines opportunities to task-shift and optimize scope. Optimization of specialized genetic professionals is necessary to maximize time spent on direct patient care and to offload clerical, operational and administrative tasks to assistive personnel.[9] Research indicates that when even one genetic assistant is added to a team, the genetics clinicians they are supporting become more productive and efficient when providing care, as less time is spent on administrative activities.[6,11]

1.2. Team members should be located in close proximity or be linked through technologies to facilitate sharing cases, sharing personal health information, and inter-professional communication and collaboration.

Co-location of clinical cancer genetics team members facilitates communication among providers, and enables more comprehensive and coordinated care through mechanisms such as joint case review and team huddles.[12] Where health care providers are not co-located (e.g., rural and remote settings), privacy and security enabled technology should be used for communication and collaboration. This technology can also help increase appropriate access to genetic counselling services and expertise to support clinical decision-making.[13] In particular, electronic consultations (eConsult)[c] could enable timely information-sharing for providers requesting guidance on appropriate ordering and interpretation of genetic tests, locating useful resources and managing care for high-risk people. Additionally, technology can be used for mainstreaming and enhancing collaboration between the clinical cancer genetics team and cancer or specialist teams (see Recommendation 5.2).

Episode of Care Recommendations

2. Standardize referral and triage processes

Appropriate screening and triage of referrals for genetic counselling is essential for ensuring that eligible people receive equitable access to care. Standardized triage allows referrals to be prioritized the same way, regardless of where someone is receiving care.

2.1. Referrals to clinical cancer genetics services should be submitted and received electronically.

Electronic referral (eReferral) systems are designed to improve wait times and efficiency by electronically standardizing information and communication throughout the referral process.[14] They automate workflow processes, such as tracking referral requests and auto-populating patient information directly from referring providers, which prevents double data entry.

Adoption of eReferral systems has been effective in supporting referring providers with streamlined and accelerated access to appropriate services for their patients, reducing administrative burden and assisting with referral completion.[14] People receiving care also benefit from shorter wait times and better access to appropriate specialists.[10] As the eReferral recipient, clinical cancer genetics services could expect more appropriate referrals, increased efficiency in referral processing (e.g., reduced administrative burden, complete referral information) and higher appointment adherence.[10,14] A provincially coordinated eReferral system would streamline and improve the efficiency of referral and triage processes (see Recommendation 8.2.2), similar to work being done by the Ontario Bariatric Network and the System Coordinated Access /Musculoskeletal eReferral service in the Waterloo Wellington Region.

2.2. Referrals should be screened, triaged, and prioritized using standardized processes.

Standardized triage ensures that referrals are prioritized the same way, regardless of where someone is receiving care. To ensure optimal access for priority patients and to manage wait times consistently, provincial recommendations should be developed that outline a consistent approach for prioritizing

[c] Family physicians and specialists can be set up to use eConsult, and can use this service directly or assign delegates to request or provide the consult on their behalf. Genetic counsellors identified as a delegate to a physician lead could also provide a beneficial service using eConsult.[c]

referrals and standardizing how urgent referrals are managed. Clinics should develop triage processes that align with provincial recommendations, and account for institutional and regional factors.

3. Optimize workflow processes to streamline case preparation

The efficient delivery of clinical cancer genetic services includes eliminating unnecessary delays, as well as managing and coordinating care before and after visits. Clinical cancer genetics teams should shift administrative case preparation tasks to genetic assistants and clerks when appropriate. They should also use technology to facilitate health history data collection and decision support, and automate as many processes as possible.

3.1. Clerks, in partnership with genetic assistants, should support case preparation by collecting all required information.

3.2. Information to help people prepare for genetic counselling (pre-appointment video, information package) should be distributed in advance of the appointment, with a genetic assistant available to help answer pre-appointment inquiries.

3.3. Technology should be leveraged to streamline case preparation tasks, such as collecting health history data, automating risk modelling and generating the pedigree.

Genetic counsellors have reported spending up to 25 percent of their time on case preparation activities that could be performed by administrative personnel.[15] Employing genetic assistants and administrative personnel (e.g., clerks) to provide administrative and operational support to genetic counsellors and physician leads enables appropriate use of specialized genetic expertise, and may improve wait times (see Recommendation 1.1).[9] To further streamline case preparation activities, getting and sending paper-based or electronic visual aids before genetic counselling appointments are another way administrative personnel can facilitate optimized workflow.[16,17]

Additionally, genetic counsellors identified reducing redundancies in documentation as key to streamlining care and improving efficiencies.[15] Electronic data collection can streamline case preparation activities, reduce duplicate data entry, increase informational accuracy and promote efficiencies in workflow.[18] Privacy- and security-enabled technology that allows people to submit their own personal and family health history electronically, and that generates automated risk estimates and pedigrees was shown to markedly reduce genetic counsellor time spent per case and streamline access without negatively impacting care or satisfaction.[18,19,20]

4. Improve access to genetic counselling through alternate settings

People should receive comprehensive and integrated cancer genetic services that meet their needs and preferences. Alternate settings to traditional in-person genetic counselling should be considered and offered, when appropriate, to improve capacity and access to clinical cancer genetic services.

4.1. Where appropriate, people should be offered a genetic counselling appointment by telephone or videoconference.

4.2. Group counselling visits should be used for patient populations that are similar and have a high-volume of referral.

Telephone and videoconferencing have been shown to improve access, reduce travel burden (for urban and rural settings), decrease wait times and promote continuity of care[19,21,22,23] without compromising

care, knowledge, satisfaction and quality of life.[19,24,25,26,27,28] While people seeking genetic counselling services have reported no disadvantages with telephone or videoconferencing, they have identified the need for technical support and efforts on the part of the providers to personalize sessions.[21] Furthermore, telephone and video counselling have demonstrated cost savings as a result of reduced overhead, travel and shorter counselling sessions.[24,29] Similar to telephone and videoconferencing, people accessing group counselling also reported high knowledge, satisfaction rates, reduced psychological distress and increased perceived control.[30] Group counselling, which can be offered virtually, has been shown to decrease provider time spent per case, allowing more people to access services and providing greater efficiency.[31]

Although overall acceptance for alternative care settings is high, individual choice should be taken into account when considering alternate settings.[24] There will always be a need for in-person genetic counselling, particularly for people with complex medical conditions or social circumstances that require more comprehensive physical assessment, counselling and support. [22,32] Irrespective of setting and format, genetic counselling services should be culturally safe and delivered in someone's preferred language. When telephone or virtual counselling sessions occur, they should adhere to best practices for virtual care. Professional interpreters are preferred, and should be available to facilitate communication and safeguard decision-making.

In addition, people offered genetic testing during a virtual genetic counselling session should be able to access genetic testing close to home. The Ministry of Health should work with provincial laboratory services to provide remote, community-based options for accessing genetic testing (i.e., specimen collection sites) at no cost to genetic clinics or people accessing genetic testing.

5. Streamline access to genetic testing for eligible people

Eligible people should have access to genetic testing facilitated by the appropriate provider, while receiving education and support. Providers should work together to improve access to genetic testing through partnerships with clinical cancer genetics teams and through partnerships with cancer and specialist team members (see Appendix D). These partnerships facilitate collaborative care, opportunities for provider continuing education and, ultimately, better access to care.

5.1. Genetic counsellors should order genetic testing for eligible patients under their care in accordance with institution specific policy.

Genetic counsellors have the knowledge, skills and abilities to determine appropriateness for genetic testing for inherited susceptibility to cancer, to explain testing options and to facilitate genetic testing.[33] However, genetic counsellors can face challenges providing services if institution-specific guidelines and policies[d] (e.g., a direct order or a medical directive) limit their ability to order genetic testing.[34,35] Eliminating the need for the physician lead to sign-off on every test ordered would allow for more timely delivery of care, and promote better use of physician and genetic counselling personnel.[35] Processes should be in place for genetic counsellors to facilitate timely consultation with, or transfer care to, the physician lead, if needed.

5.2. When appropriate, cancer team and other specialist teams (e.g., oncologist, surgeon) should work in conjunction with the clinical cancer genetics team to facilitate expedited access to genetic testing for eligible patients.

[d] Guidelines/polices should be kept up-to-date.

5.3. The genetic counsellor or physician lead should lead all results interpretation and disclosure for the tests they order, and the tests ordered by cancer team and other specialist teams.

Oncology-initiated genetic testing (mainstreaming) is better suited for specific populations that have very clear eligibility guidelines for genetic testing, and clearly defined test options (e.g., all people diagnosed with serous ovarian cancer are eligible for genetic testing).[32,36] Benefits to mainstreaming may include quicker access to testing, fewer appointments, and working with a provider who has specific oncology expertise and who is familiar to the person getting tested.[36] Obstacles to implementation may include perceived or potential burden on the cancer or specialist team.[37] However, several studies have shown high patient satisfaction with this model, as well as a positive experience for the cancer team.[38,39]

Where mainstreaming models are being established, the clinical cancer genetics team should lead initial implementation (e.g., onboarding ordering providers, including the most responsible provider), and outline the process for ongoing collaboration and consultation. This process should include coordinating specimen collection, patient re-contact and long-term follow-up.[40] The most responsible provider should consult the clinical cancer genetics team for decision support throughout this process, as needed (e.g., use eConsult to ask questions about eligibility or guidance on which test to order).[40] If someone is uncertain about whether they want to pursue genetic testing in the cancer setting or if they need additional support or comprehensive genetic counselling, the most responsible provider should refer them to genetics counselling.

Genetic counsellors and physician leads are uniquely trained in comprehensive cancer risk assessment. They have the necessary expertise and competency to provide appropriate analysis, complex interpretation and disclosure of genetic test results, as well as facilitate understanding and determine appropriate clinical management. [41,42,43,44] However, to address increasing volumes and remote geographies, cancer and specialist teams that have built and continue to maintain sufficient competency may provide results interpretation and disclosure under the advisement of cancer genetic providers.[37,42] A collaborative and consultative process ensures the accuracy of interpretation and comprehensive post-test counselling for everyone who needs it.[37,42]

Institution-specific guidelines and policies[e] (e.g., a direct order or a medical directive) may be required to disclose genetic testing results.[35] These guidelines and policies include processes for notifying and sending test results to the clinical cancer genetics team and the most responsible provider who made the referral, with the clinical cancer genetics team leading test results interpretation.[40] For tests ordered by the cancer or specialist team, variation in the results disclosure process may exist locally, based on the maturity of the program and genetics competency of the ordering provider that may have been built over time. Adjustments to this process should only be made through consultation with the clinical cancer genetics team.

5.4. Unless otherwise indicated by the person who received genetic testing, test results should be disclosed by phone and made available to them through a secure online tool.

The genetic counsellor or physician lead should provide people with their genetic testing results once they become available.[45] Providing people with access to their results via a patient portal and by phone saves time, improves access, and eliminates additional in-person appointments and associated travel. Patient portals are especially beneficial for people living in remote communities.[46] Results disclosed by phone achieve the same outcomes as results disclosed during an in-person visit[22,25, 28,47,48] and were shown to have no effect on anxiety or satisfaction levels.[49] Moreover, people have expressed greater

[e] Processes should also be in place to maintain the accuracy of these guidelines and policies over time.

satisfaction when receiving results quickly over the phone instead of waiting for an in-person visit.[45] However, when deciding whether to disclose results by phone, it is important to consider personal preference for results disclosure setting and factors such as financial or medical hardship, comprehension level and psychological well-being.[46]

6. Work with providers to ensure smooth transitions for follow-up care

Care transitions that are not well-coordinated can affect quality of care, compromise safety, decrease confidence and satisfaction with care received, and ultimately result in inefficiencies and unnecessary costs to the health care system.[10]

6.1. The genetic counsellor or physician lead should create a clinical cancer genetics follow-up care plan for their patients.

Short- and long-term follow-up care planning is an essential component of clinical cancer genetic services. Providers and their patients benefit when planning is clear, concise, readily accessible, and clearly documents the roles and responsibilities of each person involved in follow-up (including the person receiving follow-up care).[10,37,50]

Everyone receiving follow-up should have a personalized, unified clinical cancer genetics follow-up care plan. The plan should:

- outline general surgical or other treatment options, surveillance, screening, lifestyle modifications and prevention options that are consistent with the needs and preferences of the person receiving follow-up;[41,51]
- provide guidance and tools for communicating results and implications to family members;[41,51]
- identify support providers, groups and resources;[41,51]
- provide instructions to re-contact the clinic if there is a change in health history; and
- identify providers responsible for managing treatment, surveillance or screening. [41,51]

6.2. The genetic counsellor or physician lead should connect their patients to the most responsible provider to manage clinical cancer genetics follow-up care.

For people transitioning from clinical cancer genetic services, there are three main pathways for follow-up care or care management. The clinical cancer genetics team may:

- arrange for follow-up within the genetics clinic;[f]
- connect the person who received genetic services back to their primary care provider for care management; or
- refer them for specialized care (e.g., specialist, specialty clinic or established screening program).

Regardless of the transition pathway chosen, it is the responsibility of the genetic counsellor or physician lead to identify and connect their patient to the providers responsible for ongoing care management, including documented follow-up care.[41,44] Primary care providers should be informed of any subsequent referrals for specialized care, receive reports from those visits and be notified when care transitions back to them.[41]

Specialist providers accepting patients for follow-up care management may be difficult to find everywhere in the province, especially in rural and remote locations. Therefore, genetic counsellors

[f] Genetics Clinics with local capacity and expertise may offer follow-up as needed.

need help identifying specialist providers who will accept high-risk patients for care management and follow-up. Developing and administering an approach for identifying providers with the expertise and capacity to accept high-risk patients would need to be undertaken at the system level. Technology should be used to help patients overcome geographical barriers in accessing providers for follow-up care, including telephone, videoconferencing and partnering with existing telemedicine sites. Ontario's existing provider registries could be used or expanded to facilitate this process (e.g., find a doctor or nurse practitioner service,[g] the Ontario Telemedicine Network Health Services Directory).[h]

Genetics clinics should develop policies and processes for patient re-contact and follow-up that are appropriate to their practice settings and people they serve. Follow-up and re-contact are shared responsibilities among all members of the clinical cancer genetics and extended care teams, patients and family members.[52] People receiving follow-up should be informed that they have the right to be re-contacted and can decline re-contacting. People who consent to being re-contacted should be told to inform their provider of any relevant changes to their medical or family history and to ensure that their provider has their up-to-date contact information.[52] People should be able to opt-in to electronic reminders and notifications through the patient portal or other electronic tool to help facilitate this process.[10,53]

7. Provide equitable access to information, navigation, and support

Patients identified the need for timely, accessible information at all stages of their experience with cancer genetic services.

7.1. Patients receiving genetic counselling should have access to their genetic personal health information, appointment information and support resources through a secure patient portal.

Online patient portals are emerging as an important tool for improving communication between health care providers and their patients, and as a way to empower people to become more engaged in managing their health care.[54]

Aligned with the Digital First for Health Strategy,[55] implementing patient portals in clinical cancer genetics services would facilitate timely sharing of essential information (e.g., care plans, test results), promote patient navigation and care coordination, and improve outcomes and treatment plan compliance. It would also provide appointment, visit and test reminders, and link patients to educational resources.[56]

Implementing a patient portal requires prioritization and investment at the institutional or system level. While regional and institutional flexibility may be required with the implementation, portals should be interoperable and facilitate the integration of sources (i.e., have the ability to collect information across sites, hospitals, organizations).

7.2. Patient navigation throughout the episode of care is the responsibility of the clinical cancer genetics team and should be provided by the most appropriate team member (e.g., physician lead, genetic counsellor etc.).

Patient navigation is meant to proactively orient, guide and support people through the health care system by matching their needs to appropriate resources. Effective navigation can decrease

[g] Find a doctor or nurse practitioner: https://www.ontario.ca/page/find-family-doctor-or-nurse-practitioner
[h] Ontario Telemedicine Network Health Services Directory https://otn.ca/providers/specialist-allied/directory-specialist/

fragmentation, improve access and promote the integration of care. Patients have identified consistent navigation as a key need throughout the clinical cancer genetic services episode of care.[10]

Navigation through the cancer genetics services episode of care is the combined responsibility of the genetic counsellor, genetic assistant and clerk. Ideally, the clinical cancer genetics team should provide a clear point of contact that remains consistent for the person getting genetic counselling (i.e., consistent email or phone number). The choice between a clinical (e.g., genetic counsellor or genetic assistant) or administrative (e.g., clerk) navigator generally depends on the type of navigational support required, someone's individual needs and setting. The clinical cancer genetics team is responsible for providing appropriate navigation based on the needs of the person receiving genetic counselling.

System-Level Recommendations

8. Establish provincial oversight for clinical cancer genetics services

Provincial administration and oversight are needed to standardize and coordinate the delivery of high-quality, efficient and equitable clinical cancer genetic services across Ontario. A provincial program would be responsible for:

- system-level operational oversight, such as continuous capacity planning, and developing standardized clinical guidance, criteria, processes, tools, templates and other supportive resources;
- continuous quality improvement and performance management enabled by clinician and patient engagement, centralized data collection, reporting, monitoring and setting targets;
- advocacy, education, facilitation and change management, including clinical leadership (e.g., the head of the provincial program at Ontario Health [Cancer Care Ontario]) and champions; and
- supporting the implementation and spread of new processes and practices (e.g., mainstreaming) to facilitate uptake and buy-in, ensure consistency and reduce regional burden.

The benefit of central administration and oversight is a standardized and coordinated approach to genetics service delivery that promotes equity, access and efficiency, while minimizing unnecessary variation, duplication and redundancies.

8.1. Develop a comprehensive and sustainable funding plan for clinical cancer genetic services delivery that includes operational and volume-based allocations.

Dedicated health and human resource funding is needed to address existing gaps based on capacity, and demand modelling is needed to address current and future demand. The Ministry of Health should work with Ontario Health and leading experts to create sustainable funding models for cancer genetic services. These models should be based on volume targets and quality measures that include allocations for physician leads, genetic counsellors, genetic assistants, clerks, provider education and professional development. The models should also align with closely related programs and services (i.e., high-risk screening programs, hereditary cancer testing).

Additionally, funding is needed to operationalize these recommendations in the form of an enhanced model of care for clinical cancer genetic services delivery. The funding should cover implementing a provincial program, eConsult, virtual visits, systems, and tools to support navigation and communication. The development of this funding plan should be informed by engaging regional genetic service providers to ensure that an appropriate number of skilled resources are available across the province in urban and rural locations.

8.2. Implement standardized resources and tools for providers and their patients that help ensure high-quality care delivery and patient management.

8.2.1. Develop, endorse and share standardized clinical guidance for cancer genetic services across the province.

8.2.2. Referral should be provincially or regionally coordinated and supported by a provincially standardized electronic referral platform.

Referral processes vary significantly, therefore, consistent guidance regarding cancer genetic services eligibility should be developed and endorsed provincially to ensure appropriate use of highly specialized and in-demand resources. Wait time targets should be developed and monitored to ensure timely access to genetic counselling. The province should also work with molecular testing laboratories to adopt standardized provincial requisition and electronic ordering to facilitate streamlined ordering of hereditary cancer tests.

Regional or provincial standardization and coordination of referrals for clinical cancer genetic services would support equitable access. It would also alleviate single clinic capacity constraints by managing referrals between genetics clinics, as necessary, based on factors such as wait times and availability of specialized care. Additionally, using a provincially standardized electronic referral platform would support ongoing performance monitoring, reporting and target setting.

8.2.3. Develop, endorse and share standardized genetics education resources across the province.

People accessing genetic counselling services have reported difficulty finding the right level of information to meet their needs at each stage of their cancer genetics care.[10,57] Tailored education can increase genetic risk awareness, visit preparedness and overall satisfaction with genetic counselling.[55,58] This is especially true for underserved and minority populations when tailored education accounts for their cultural, linguistic, educational and literacy needs.[58] Patients have reported high satisfaction when they are provided with genetics care educational materials, such as internet-based educational videos, presentations and general genetic information.[55,58,59]

Patients should have access to standardized educational resources, such as videos or visual aids that are available electronically and in paper format.[10] The development and dissemination of education material (e.g., pre-appointment video, information package) should be coordinated at the system or provincial level, while allowing flexibility to tailor content for specific populations and local contexts. Existing education materials should be used where possible to reduce duplication of efforts. An educational website or online community portal for the province would help facilitate the sharing and dissemination of resources. Educational resources should be developed based on educational theory, clinical guidelines and practice experience, as well as end-user (i.e., patients, families and counsellors) feedback.[58]

8.2.4. Develop, endorse and share standardized training and resources for providers across the province.

Developing standardized provider resources, clinical standards and guidance, processes, training and tools should be facilitated at the provincial level, which clinics could then tailor to their local context. This provincial standardization is particularly beneficial for the scale, spread, and adoption of new practices and processes, such as mainstreaming. Developing and endorsing resources such as provincial eligibility criteria, orientation and training resources to onboard providers would enable change management while reducing regional burden and duplication of efforts. Provincially standardized

resources may be especially useful for smaller and general clinics that may not have enough human resource capacity to maintain an up-to-date database of resources. Additionally, the province could implement infrastructure to enhance knowledge transfer, collaboration and information-sharing across sites, including supporting policy development at individual clinics. All clinical cancer genetic team providers should be encouraged and enabled to pursue continuing education to strengthen scope of practice development at their respective institutions.

8.3. Integrate information management/information technology resources and electronic tools to facilitate secure sharing and receiving of personal and family health data, risk modelling and pedigrees and facilitate efficient case review.

The province must adopt secure, integrated electronic tools for receiving personal and family health data, generating risk modelling and generating pedigrees. These tools will eliminate paper-based processes, enable automation and facilitate efficient case review. Implementing these electronic tools would ensure that all clinics, and therefore their patients, would have equal access to information. It would also enable integration and secure transmission of patient history and risk modelling data across the province. Standardized training on the use and functionality of the electronic tools should be offered to all clinical cancer genetic teams on an ongoing basis.

8.4. Develop a provincial genetic testing results registry or database to support accurate and efficient clinical decision-making and surveillance.

Genetics is a data-intensive field, which requires the use of technology and health information platforms to increase efficiencies, advance knowledge in the field, and help identify and monitor people at risk of developing a hereditary cancer. A provincial registry or database should be implemented to house genetics results and support patient management, collaboration, surveillance, planning and research. Quality assurance metrics should be developed to ensure efficacy of the registry or database, and provide reporting and performance management.

Implementation Considerations

Regional Variation and Tailoring to Local Context

Patient populations, geography, available resources and the level of expertise among providers vary significantly across the province, leading to unique local challenges and opportunities in each region. Implementing the recommendations outlined in this document should allow for regional flexibility and tailoring to local contexts.

Prioritization and Phased Implementation

Successful implementation of this enhanced model of care will require a multi-year phased approach and mobilization of resources at local, regional and provincial levels. Short-term goals could focus on recommendations that require little financial investment to realize improvement. Specifically, immediate action could be taken to improve efficiency and capacity through:

- standardizing processes (2.2, 3.3, 5.1, 5.3, 6.1, 7.2, 8.2 [8.2.1-8.2.4]);
- optimizing scope of practice through task-shifting or by investing in administrative support (1.1, 3.1, 3.2, 4.1, 4.2); and
- use existing technology such eConsult, the Ontario Telemedicine Network and other technologies that are provincially available (1.2, 4.1, 8.2).

While local agreement is required to move forward on the recommendations, provincial-level oversight should also be in place. Through its partnerships with the Regional Cancer Programs and the five transitional health regions, Ontario Health is well-positioned to help coordinate and implement these recommendations by supporting change at the clinic level, aligning priorities to Ontario's Digital Health Strategy and other related initiatives (e.g., cancer screening, hereditary cancer testing), and leading the planning and prioritization of longer-term recommendations.

The direction and commitment to system-level improvements should be established as early as possible in the implementation process to avoid duplication and wasted effort at the clinic level. Although these recommendations were created with a clinical cancer genetic services lens, many of the recommendations are transferrable to genetic services more broadly.

Technology Security and Integration

Although patients acknowledge the significant benefits and value of technology-enabled care delivery, they want the confidentiality and security of their personal health information to be ensured. Technology and infrastructure employed for information-sharing must have the appropriate legal, privacy and security safeguards in place to protect personal health information and comply with legislation.

Privacy concerns and lack of funding may prohibit many clinics from using technological platforms, such as electronic pedigree software, patient portals and e-referral platforms. Employing a provincial approach to identifying and selecting technology solutions would enable cost-effective implementation and integration, and prevent regions from having to navigate issues such as privacy, security and user training. Additionally, the use of province-wide technology platforms would enable data collection, reporting and monitoring to ensure continual quality improvement.

Integration and connectivity across platforms are important considerations when selecting technology solutions at the site level, as are usability, system performance, interoperability, cost and end user

engagement. However, not all people seeking genetic counselling have access to or use technology. Therefore, alternative mechanisms would need to be in place to ensure that they benefit from the same high-quality care.

Training and Education

Academic colleges, universities, professional colleges and associations play an important role in building a skilled workforce and creating awareness about the practice of genetic counselling. Education on general medical genetics should be embedded in university and college curricula for all providers of genetic services, including medical, nursing, allied health and administrative personnel. Standardized certificate programs, which currently do not exist, should be developed for clerical staff and genetic counselling assistants. These programs should be developed in collaboration with professional colleges and associations with investment from the province.

Enrollment for genetic counselling programs and medical geneticist fellowships should be expanded based on the outcomes of provincial health human resources planning. Collaboration with professional colleges and associations could also help expand the presence of cancer genetic services in health care and increase licensing for genetic counsellors.

Appendices

Appendix A: Cancer Genetic Services Model of Care Working Group - Terms of Reference

Background

Hereditary cancer accounts for approximately 5-10% of all cancer incidence.[i] The number of genes identified that can play a role in the diagnosis and management of hereditary cancer syndromes (HCS) has increased steadily over time. Traditionally, genetic counselling has been a prerequisite to genetic testing for hereditary cancer. Increase in demand for genetic testing has significantly impacted the need for genetic counselling, leading to inequity in patient access, long wait times, and variation in the delivery and quality of care.

In response to concerns raised by CCO Regional Vice Presidents about access to genetic services and long wait times, CCO formed the Clinical Genetic Services Working Group to perform a current state assessment and to develop recommendations for improving genetic services across Ontario. In 2018, CCO released a recommendation report highlighting the need for governance and oversight, improved patient access to genetic services and to standardize practice.

The current state assessment revealed that cancer referrals to genetic services almost tripled (from 6378 to 18084) between 2007 and 2016 while health human resources remained static, leading to long wait times. The Models of Care work will focus on capacity and service gaps and develop recommendations to optimize processes of cancer genetic services, service delivery and health human resources.

Scope

The Cancer Genetic Services Model of Care Project seeks to determine a preferred model of care to enable more timely and improved access to genetic services for hereditary cancers by optimizing processes in care, the use of health human resources and care settings.

Deliverables

The purpose of the Cancer Genetic Services Model of Care Working Group ('Working Group') is to develop a detailed model for cancer genetic services by:

- Clarifying the roles of the interdisciplinary team members;
- Improving processes associated with cancer genetic services (including triage/intake, assessment, counselling, accessing genetic testing and follow-up); and
- Identifying challenges and enablers for implementing the recommended model of care.

Term of Engagement

The term for this Working Group is from September 2019 to June 2020.

- Members will be asked to attend meetings via teleconference or in-person and provide feedback on draft documents and meeting materials by email.

[i] Cancer Care Ontario (CA). Recommendation report for Ontario's clinical genetic services. Ontario (CA). Cancer Care Ontario; 2018.

- If unable to attend scheduled meetings, the members are encouraged to review meeting notes and materials and connect with other Working Group members or the CCO team to provide input.

Membership

Patient and family advisors, health care professionals and administrators currently engaged in the care of the in- scope patient populations (in alphabetical order):

- Co-chair, Clinical Lead for Pathology and Laboratory Medicine (1)
- Co-chair, Genetic Counsellor (1)
- Patient and family advisors (2)
- Genetic Counsellor (9)
- Medical Geneticist (2)
- Medical Oncologist (2)
- General Practitioner (1)
- Surgeon (1)

The Co-chairs of the Working Group are responsible for providing direction to the group, setting meeting agendas, chairing meetings, and facilitating discussions.

Decision-Making Process

Decisions will be made by consensus of the members. If there are any issues on which consensus cannot be achieved, the decision-making approach will be decided upon by the Co-chairs, in consultation with the Personalized Medicine Steering Committee.

Accountability

The Working Group is accountable through its Co-chairs to the Personalized Medicine Steering Committee.

Conflict of Interest

Working Group members must ensure that any actual or potential conflict of interest concerning any matter under discussion by the committee is drawn to the attention of the Co-chairs. The Co-chairs will decide what action, if any, is required arising from the conflict of interest and will take appropriate action, including but not limited to requesting the member absent him or herself from participation in discussion of the matter. Members will be required to complete a Conflict of Interest Declaration upon joining the Working Group.

Confidentiality

Unless it is generally available to the public, all data and information acquired or prepared by or for the committee should be treated as confidential. Members should keep these data and information confidential and not directly or indirectly disclose them during or subsequent to their term as a member of the committee.

Members will be required to complete a Statement of Confidentiality upon joining the Working Group.

Appendix B: Clinical Cancer Genetic Services: Patient Focus Group Facilitation Guide

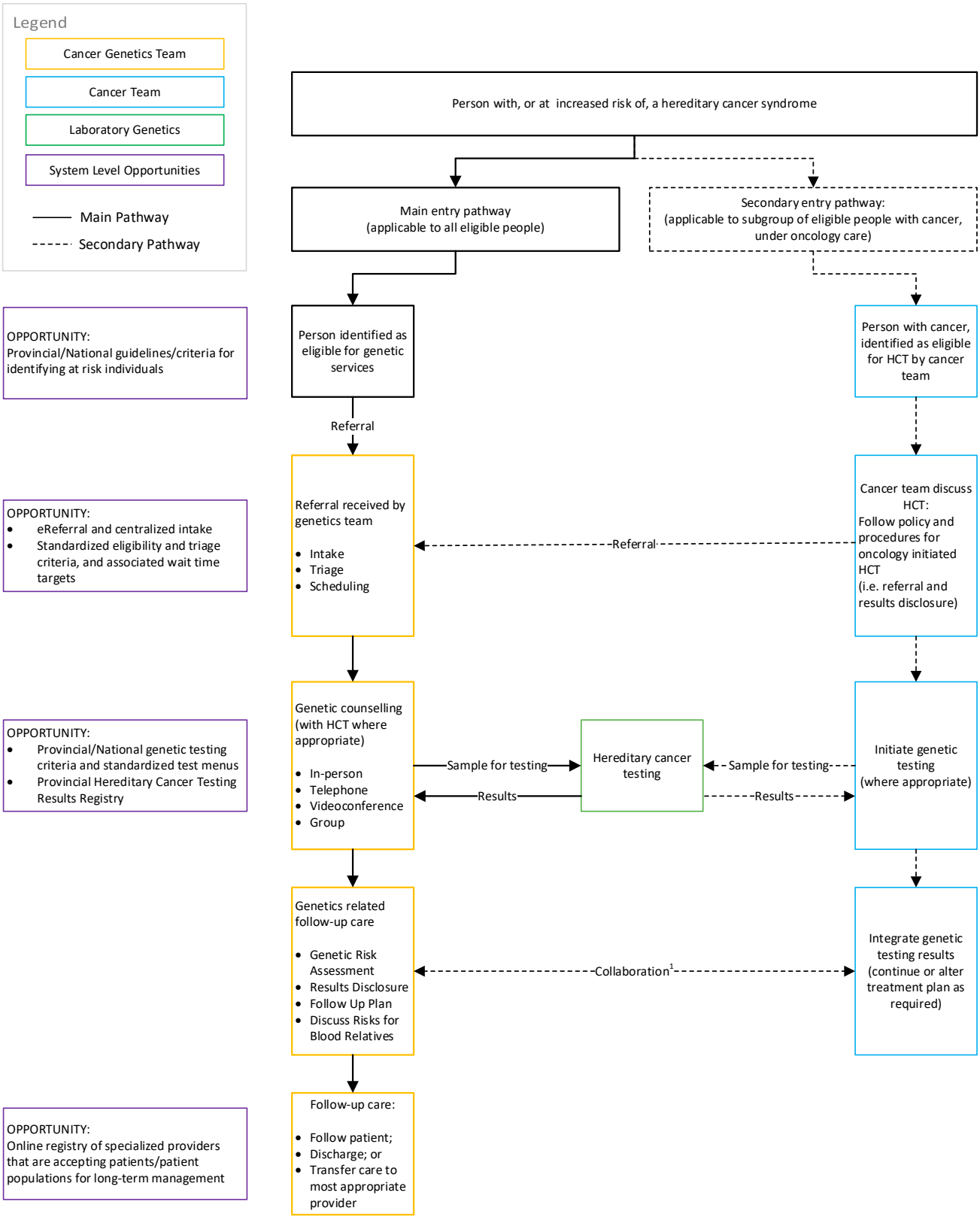
Stage	Considerations	Questions
1. Intake (includes intake, triage and scheduling)	• Prior to receiving counselling, patients may experience any of the following: o Follow up questions from providers based on their referral form o Need to schedule an initial counselling session o Provide personal and family health history o Receive education about general genetics, genetic counselling and genetic testing. • Information/resources may be shared: o verbal, written, online, mail • During this phase, several factors can impact the patient experience. Examples include: o Wait times or access o Multiple providers involved (genetic counsellors, nurses, patient navigators, clerks etc.) o Navigation o Communication (timeliness, method, frequency, etc.) o Next steps	Overall Experience: • How did you get referred for genetic counselling? (i.e., did you initiate the conversation with your doctor, or did they bring it up? (Primary care? Oncologist? Family member? Self-identified?) • How did you feel about being referred for genetic counselling? • **What happened during this stage?** Who contacted you / who did you speak with? What was discussed? What was the experience like? • **How much were you informed about what to expect from genetic counselling?** Were you informed about how genetic counselling would proceed? Who you would meet with, how you would meet (e.g. in-person, handout, video, telephone etc.) and what would be discussed? • **Were you asked how you preferred to receive care (phone, videoconference, in-person, email etc. or combination)?** Scheduling and Triage • How was your genetic counselling appointment scheduled? Where there any tools offered to help with this process (reminders etc.)? • **How long did it take to see the genetic counsellor from the time you were referred?** Was this a reasonable amount of time? • Did someone contact you to coordinate or navigate your care? Support: • **Was there any form of support offered to address any questions?** • What type of resources were provided? How were they provided? • Do you feel that you were provided enough information regarding what to

Stage	Considerations	Questions
		expect during counselling and how to prepare for it? If so – what worked well? If not, what would have helped make this process better? Next steps: • **Were the next steps in your care discussed and were they clear?** • Did you know who you were going to see next? • Were you told when you would be contacted next?
2. Counselling (includes genetic counselling session and testing)	• During this phase, several factors can impact the patient experience. Examples include: o Location of the session o Providers (geneticists, genetic counsellors, nurses, etc.) o Privacy and confidentiality concerns o Review / confirm family history / pedigree / inheritance o Provision of patient education and assessment of patient understanding o Psychological assessment o Psychosocial assessment o Family dynamics o Opportunity for patient questions o Consent and scheduling of testing o Results of testing o Other o Next steps	Overall: • **What was your experience receiving counselling?** Location, providers, information discussed? Counselling: • **What did you discuss with the counsellor, is that what you expected?** • **How did you communicate with the counsellor?** In-person, phone etc.? • What could have been performed better/more efficiently? Genetic Testing: • **Did your experience include genetic testing?** • What providers did you interact with during genetic testing? • **Did you have to wait for testing? If so, how did the wait affect you?** • Did you travel to get to your appointment(s) or to be tested? • How did you feel about your travel? • Did you have to book additional appointments for sample taking/blood draw? • How long did you have to wait for test results and how were your results given to you? • **What worked well and what could have been done better?** Support:

Stage	Considerations	Questions
		• What did you do if you had questions about your session or testing? • Did you feel like your questions were answered during session? • Did you feel like the providers assessed your understanding of the information discussed and responded to your needs in session and/or provided a contact for follow-up? • **Did you feel like you had enough knowledge to make an informed decision about testing?** Did you have any hesitation about testing? Why or why not? Next steps: • **Were the next steps in your care discussed?** • Did you know who you would see next?
3. Follow-up (includes getting results and long-term follow-up)	• Short- and long-term follow-up • Follow-up based on type or result (negative, positive, VUS,) • Providers involved • Aspects of the experience to consider include: o Communication (timeliness and method) o Appointment types (phone, in-person, video, combinations?) o Navigation o Next steps • Suggestions for improving experience with genetic counselling and/or testing? o Anything else that worked well and shouldn't change? o Any barriers to access?	Overall: • **What happened when you received your results?** • How were your results communicated to you, by whom, where? • Did you feel like you understood your results? How so? How not? • What did you like/not like about when you received your results Details about the follow-up period: • Was there any follow-up? With whom? How often? • How was communication provided (in-person, phone, etc.)? Support: • Were you offered any support post-test? From whom and for what? How accessible was this support? • Was there a process to inform family members of the results, how did you feel about that? • **Did you feel like you had enough knowledge after your session?**

Stage	Considerations	Questions
		• Was there any form of support to address any questions? Next steps: • **Were the next steps in your care discussed?** • Was there a "hand-off" of to another provider? • Is there anything we missed today that you want to discus

Appendix C: Patient Pathway



[1]This collaboration is defined based on local/institutional/regional factors and decisions, and may vary across the province.

Appendix D: Provider Table

This appendix describes the roles and responsibilities of the members of the core and extended teams in the enhanced model of care.

Clinical Cancer Genetics Team

Provider Type	Description	Role in Genetic Services Model of Care	Regulatory Status and Qualifications
Physician lead (medical geneticist, or oncologist /physician with expertise in clinical genetics)	For hereditary cancer genetics, this role can be filled by a medical geneticist or medical doctor (i.e., medical oncologist, surgical oncologist or primary care physician) with expertise in clinical cancer genetics (as defined by their professional college and scope-of-practice requirements)	• Creates clinical process guidelines and polices for the clinic • Provides leadership and consultation to genetic counselling and support staff • Provides leadership and advice to genetic counsellor regarding: o screening and triage of complex cases o challenging or complex cases (provides oversight, consultation or transfer of care) • Provides genetic counselling services to patients and their families when genetic conditions are diagnosed, and must inform referring practitioners about the implications, prognosis and risks associated with the genetic disorder • Consults on and accepts referrals for complex cases (within their area of expertise) • Determines and orders the most appropriate testing for people with complex personal and family histories, and provides interpretation • Provides specialized care for complex cases, including assessing people directly or through consultation – cases should be assigned directly to the physician lead for: o strong suspicion of a syndromic condition that may require a physical examination o complex clinical interpretation	Regulatory status: self-regulated and registered to practice through the College of Physicians and Surgeons of Ontario Qualifications (medical geneticist): After completing medical school, an additional 5 years of Royal College-approved residency training is required to become certified in medical genetics. This training includes: • 2 years of training in pediatrics, internal medicine, genetics and obstetrics, followed by a Canadian College of Medical Geneticists-approved fellowship • 3rd and 4th years are spent doing rotations in clinical genetics and laboratory work in cytogenetics and biochemical and molecular genetics • 5th year includes clinical genetics, research or training in other areas

Provider Type	Description	Role in Genetic Services Model of Care	Regulatory Status and Qualifications
		○ further medical investigation (blood work, skin biopsy, imaging) to aid in variant interpretation or phenotyping • Provides consultation to non-genetics providers who initiate genetic testing and supports follow-up care • Facilitates referrals to extended team members who can lead follow-up care recommendations, as needed • Provides long-term management (prevention, screening and/or treatment) for select populations • Educates people with genetic disorders, providers and the public	For further details on training requirements please go to Royal College of Physicians and Surgeons of Canada, Canadian College of Medical Geneticists **Note:** There are 2 designations for medical geneticist, Fellow of The Royal College of Physicians of Canada and Fellow of the Canadian College of Medical Geneticists – in Ontario, these are equivalent for employment purposes and Ontario Health Insurance Plan billing
Genetic Counsellor	Genetic counsellors are health professionals with specialized training and experience in the areas of medical genetics and counselling – genetic counsellors work as members of a health care team, providing individuals and families with information on the nature, inheritance and implications of genetic disorders to help them make informed decisions[60]	• Helps make counselling eligibility determination and triage decisions • Conducts genetic assessments, which includes retrieving and reviewing appropriate medical records or other relevant information, conducting the necessary review of literature and protocols, determining appropriate risk figures for individuals and family members, reviewing cases with a geneticist or physician lead when necessary • Provides genetic counselling to individuals and families • Accesses psychosocial services, acts as patient advocates and refers individuals and families to available support services • Initiates genetic testing, if appropriate (medical directive) and communicates results • Facilitates referrals to other health care providers • Liaises with colleagues, internal and external health care providers and other agencies to ensure continuity of care through counselling, testing, results and follow-up • Participates in the ongoing quality improvement activities	Regulatory Status: Unregulated Qualifications: • Master's degree in genetic counselling • Certification / eligibility for certification by the Canadian Association of Genetic Counsellors and/or American Board of Genetic Counselling • Meet Canadian Association of Genetic Counsellors core competencies[61]

Provider Type	Description	Role in Genetic Services Model of Care	Regulatory Status and Qualifications
		• Participates in educational and professional development activities • Liaises with non-genetics providers, participates in multidisciplinary case conferences or review multidisciplinary case conferences patient lists to help identify people who would benefit from referral to genetics • Educates patients, their families, providers, and the public	
Genetic Assistant /Genetic Counsellor Assistant	Genetic counselling assistants work in collaboration with the genetics team to ensure that patients have a positive experience during all services, from receipt of referral to follow-up	• Central point of contact for inquires and care navigation • Provides ongoing operational support to physician leads and genetic counsellors • Responsible for data entry and database management (pedigree software tool, electronic medical record, risk assessment tools) • Organizes and prepares patient charts for a variety of genetic consults, gets complete family histories, prepares pedigree information, retrieves appropriate medical records and other relevant information • Organizes, coordinates and tracks genetic testing results, out-of-country applications, medical records, physician requests and family history questionnaires • Assists with screening or triaging, case preparation and post-appointment activities • Assists with research studies, chart audits and other educational opportunities	Regulatory status: Unregulated Qualifications: • Completion of, or working towards, a Bachelor of Science in biology or genetics from an accredited university, or equivalent Or • Completion of, or working towards, an undergraduate degree from an accredited university
Clerk	Leads administrative tasks and provides operations support, such as scheduling, referral processing, and managing patient inquires	• Processes referrals, including requesting missing information or redirecting incorrect referrals • Schedules appointments, including responding back to referring providers regarding referral status and appointment timing according to College of Physicians and Surgeons of Ontario guidelines	Not applicable

Provider Type	Description	Role in Genetic Services Model of Care	Regulatory Status and Qualifications
		• Manages and triages inquiries • Supports genetic assistant in maintaining and updating pedigrees	
*Clinical Genetics Manager	Manages clinical cancer genetics programs and services	• Plans and organizes quality cancer genetic service delivery according to operational guidelines, and according to institutional, regional and population demographics and needs • Oversees recruitment and retention of genetics team, as well as adherence to certification requirements, accreditation standards and standard of care guidelines • Maintains positive stakeholder relationships with referring providers and coordinated or collaborating services • Monitors for opportunities to improve in the domains of quality metrics, financial performance and person-centred care • Identifies and coordinates efforts to implement quality improvement initiatives • Sustains consistent communication and advocacy for cancer genetics with senior leadership teams, tables and provincial oversight organizations, ensuring that a strong governance structure is in place	Not applicable

*In addition to the minimum core team, this role (i.e., the clinical genetics manager) is recommended. This role may be a dedicated or shared resource, depending on the size and complexity of the clinic and population served.

Extended Team

Extended Team/Providers	Role in Cancer Genetics Model of Care	Providers
External genetics teams	• Engage in local and provincial collaboration, knowledge sharing, consultation and transferring of care with other genetics teams	Genetic counsellors, medical geneticists, oncologist or physician with training or experience in clinical genetics
Cancer team	• Plays a supportive role in initiating access to genetic testing for people with cancer, treatment, psychosocial support, long-term management and follow-up care • Maintains a close relationship with the core cancer genetics team	Oncologists, surgeons, registered nurses, general practitioner in oncology, physician assistant, clerk
Laboratory services – molecular genetics	• Actively contributes to the study of genetic disease and the advancement of genetic testing and related technology, with a goal of enhancing clinical care • Provides technical expertise and consultative services • Ensures that accurate, reliable results are available in a timely manner – collaborates with core genetics team on test selection and results interpretation	Laboratory/molecular geneticist
Laboratory services – molecular genetics	• Actively liaises between the ordering provider and molecular oncology laboratory to facilitate appropriate and timely hereditary cancer testing • Works collaboratively within molecular oncology lab to ensure accurate, reliable results (i.e., there are labs where the genetic counsellor co-signs reports) • Participates in variant interpretation, including working with ordering providers to gather relevant clinical information to assist in determining significance	Laboratory genetic counsellor

Extended Team/Providers	Role in Cancer Genetics Model of Care	Providers
Pathology and laboratory medicine	• Works collaboratively with the clinical genetics team to develop processes for incorporating genetic test results into pathology reports • Alerts ordering providers when to refer people to genetics based on pathology findings	Pathologist
Primary care	• Identifies appropriate patients for referral to clinical genetic services • Provides long-term management, and follow-up care; when required, transitions care to appropriate providers	Primary Care Physician, Nurse Practitioner
Psychosocial support service providers	• Provides emotional supportive care to reduce anxiety associated with the genetic testing process and results • Provides people getting genetic counselling and their families with support resources, including peer support options (e.g., online forums, educational webinars)	Social Worker, Psychologist, or Peer Support Groups
Information technology and analytic support	• Provides information technology support for existing technologies and new project implementations • Provides data analytic and decision support	Analyst

Appendix E: Activity Table

Standardize Referral and Triage

Referral, Triage and Scheduling Activities	Baseline	Future	Considerations and Enablers
Screen referrals using a standardized process to determine eligibility for genetic counselling	Genetic counsellor, physician lead	Genetic assistant, clerk, genetic counsellor, automated	Provincial counselling eligibility criteria should be regularly developed, reviewed and updated through expert consultation A standardized referral screening process should also be developed to help administrative personnel conduct preliminary or high-level referral screening and automate processes using technology
Consult on complex cases for eligibility determination	Physician lead, genetic counsellor	Physician lead, genetic counsellor	Not applicable
Triage referrals using a standardized process, including identifying urgent referrals (for timely treatment decisions and medical management) and appropriate wait listing, to determine the recommended setting for genetic counselling delivery (individual or group – in-person, telephone or videoconference)	Genetic counsellor/physician lead	Genetic assistant/genetic counsellor	A standardized eReferral process and electronic form is required to ensure completion of necessary information Provincial triage criteria should be regularly developed, reviewed and updated through expert consultation, which should accompany protocol to be followed by a genetic assistant (with oversight from genetic counsellor/physician lead) – wait listing protocol should also be developed through a similar process

Referral, Triage and Scheduling Activities	Baseline	Future	Considerations and Enablers
Consult on complex cases for triage decision	Physician lead, genetic counsellor	Physician lead, genetic counsellor	Not applicable
Acknowledge referrals in accordance with College of Physicians and Surgeons of Ontario guidelines (no later than 14 days from the date of receipt), including whether or not the referral is accepted	Clerk	Clerk or auto generated	Auto-generated referral confirmations and eligibility determination notifications to referring providers are needed for care accountability and to streamline paper and fax processes – eReferral processes should also include these functionalities training of administrative staff
Send acknowledgement of accepted referrals, including wait time or appointment date	Clerk	Clerk or auto generated	Auto-generated referral confirmations and eligibility determination notifications to referring providers are needed for care accountability and to streamline paper and fax processes – eReferral processes should also include these functionalities training of administrative staff
Decline incomplete referrals and send back to the referring provider noting outstanding information	Clerk	Clerk or auto generated	Auto-generated referral confirmations and eligibility determination notifications to referring providers are needed for care accountability and to streamline paper and fax processes – eReferral processes should also include these functionalities training of administrative staff
• Decline referrals that are incorrect or ineligible and notify referring provider: o genetic assistant outlines reasons for declining referral using a pre-approved template o genetic counsellor reviews and approves	Genetic counsellor	Genetic assistant (with oversight of genetic counsellor)	Auto-generated referral confirmations and eligibility determination notifications to referring providers are needed for care accountability and to streamline paper and fax processes – eReferral processes should also include these functionalities training of administrative staff
Manage and triage inquiries via email, phone, mail, fax and online	Clerk	Clerk	Not applicable

Referral, Triage and Scheduling Activities	Baseline	Future	Considerations and Enablers
Book appointments and send reminders	Clerk	Clerk, automated	The automatic appointment reminder functionality should be a feature of the patient portal development
Communicate with patients and their families in person, via telephone, and via patient portal regarding scheduling updates	Clerk	Clerk	Not applicable

Reduce Time Spent on Case Preparation

Genetic Counselling Preparation Activities	Baseline	Future	Considerations and Enablers
Collect personal and family health history through an online pedigree program, as well as through paper or phone-based surveys	Genetic counsellor, clerk	Genetic assistant, automated, patient	Provincial adoption of a secure electronic pedigree tool that enables secure electronic collection of information to streamline data collection and avoid redundancies is needed Maintaining privacy and confidentiality is paramount to implementation of this tool
• Provide technical support to facilitate use of the pedigree program	Clerk	Clerk	Training on the use of the pedigree program should be provided to clerks by Genetic assistants or genetic counsellors, and should be standardized across the province
• Transfer information from paper- or phone-based surveys into the electronic platform.	Genetic counsellor	Clerk	Training on the use of the pedigree program should be provided to clerks by Genetic assistants or genetic counsellors, and should be standardized across the province

Genetic Counselling Preparation Activities	Baseline	Future	Considerations and Enablers
• Answer patient inquires related to care navigation, data requests, and other genetic health related inquiries	Genetic counsellor	Genetic assistant, genetic counsellor	The patient information website should be used as the primary tool to facilitate navigation and requests for health information Genetic assistants should receive standardized training on all components of the patient information website
• Request and review outside patient records	Genetic counsellor	Genetic assistant	Provincial adoption of a genetic testing results registry or database may facilitate information sharing of external records Privacy considerations need to be addressed in the capture, maintenance and use of this personal health information
• Complete literature review	Genetic counsellor	Genetic assistant or genetic counsellor	Not applicable
• Run risk models	Genetic counsellor	automated	Secure generation of risk models and family trees should be functionalities in the provincial electronic pedigree tool
Summarize and prepare cases for genetics team to review before appointments	Genetic counsellor	Genetic counsellor	Genetic assistants should receive standardized training on case preparation and criteria should be developed to determine scope of cases for team review
• Participate in genetics team meetings and huddles to streamline review of complex cases	Genetic counsellor, physician lead	Genetic assistant, genetic counsellor, physician lead	Genetic assistants should receive standardized training on case preparation and criteria should be developed to determine scope of cases for team review
Distribute visual aids for patients	Genetic counsellor	Genetic assistant	Standardized visual aids and videos should be endorsed and shared across the province, using materials when they already exist

Genetic Counselling Preparation Activities	Baseline	Future	Considerations and Enablers
			Updates and new developments should be coordinated at the provincial level
Explore testing options	Genetic counsellor/physician lead	Genetic counsellor/physician lead	Not applicable

Improve Access to Genetic Counselling Through Alternate Settings

Genetic Counselling Activities	Baseline	Future	Considerations and Enablers
Establish rapport, agenda, goals and plans for the session • Discuss and review medical history, family history, natural history, basic genetics • Complete risk assessment and inheritance • Develop or review pedigree • Complete psychosocial assessment	Genetic counsellor	Genetic counsellor	Genetic counselling by telephone or videoconferencing, including group counselling, should be encouraged Provincial capacity planning is needed to determine health human resource requirements to ensure equitable access to genetic counselling across Ontario Funding for genetic services, including technologies, should also take into account the setting of the visit to enable equitable access to care regardless of geography
• Provide psychosocial counselling	Genetic counsellor	Genetic counsellor	Not applicable

Genetic Counselling Activities	Baseline	Future	Considerations and Enablers
Review and discuss genetic testing options, including information on the description, management and inheritance of applicable genes, as well as the risks, benefits and limitations of genetic testing	Genetic counsellor	Genetic counsellor	Not applicable
• Get informed consent	Genetic counsellor	Not applicable	Not applicable
• Complete genetic testing requisition form	Genetic counsellor	Not applicable	Not applicable
• Discuss medical management options	Physician lead/genetic counsellor	Physician lead/genetic counsellor	Not applicable

Streamline Access to Genetic Testing

Test Ordering Activities	Baseline	Future	Considerations and Enablers
Get informed consent (or legally appointed substitute-decision maker) while providing information on the benefits, limitations and consequences of proceeding or not proceeding with genetic testing	Genetic counsellor, physician lead	Genetic counsellor, physician lead, oncologist, specialist	Not applicable
• Order genetic testing through a medical directive, such as predictive cascade testing	Genetic counsellor	Genetic counsellor	Provincial support for genetic counsellor licensure/regulated health professional status Maintaining a close working relationship, the molecular oncology lab to facilitate communication about changes in testing menus, testing methodology and specimen collection

Test Ordering Activities	Baseline	Future	Considerations and Enablers
• Order testing for cases that fall outside the medical directive, such as for people who need a physical exam for certain syndromic conditions (e.g., tuberous sclerosis, neurofibromatosis, Cowden syndrome) or who need further medical investigations (e.g., bloodwork, skin biopsy or diagnostic imaging) to aid in variant interpretation or phenotyping	Physician lead	Physician lead	Not applicable
• Order testing in oncology setting for specific cancer populations (see Appendix D: Provider Table – Clinical Cancer Genetics Team)	Not applicable	Cancer team	Not applicable

Mainstreaming and Oncology-Initiated Genetic Testing	Baseline	Future	Considerations and Opportunities
Identify current cancer patients that are eligible for genetic testing based on defined criteria/guidance	Not applicable	Cancer team, most responsible provider, genetic counsellor (multidisciplinary case conferences)	Criteria or guidance for determining eligibility for genetic testing should be developed provincially Enable the cancer genetics team to attend multidisciplinary case conferences through workload management and capacity support
Incorporate genetics into existing appointment if possible: • Note or flag to include in upcoming appointment with registered nurse or doctor • Schedule dedicated appointment (clerk)	Not applicable	Cancer team	Not applicable

Mainstreaming and Oncology-Initiated Genetic Testing	Baseline	Future	Considerations and Opportunities
Get informed consent for testing while providing education about benefits, limitations and consequences of proceeding or not proceeding with genetic testing	Clinical cancer genetics team	Cancer team	Not applicable
Complete genetic testing requisition form	Clinical cancer genetics team	Cancer team	Not applicable
Refer to genetics for results disclosure	Not applicable	Cancer team	Oncology teams who have built capacity over time in consultation with the clinical cancer genetics team may disclose results where they have the competency to do so – otherwise, results disclose should be the responsibility of the clinical cancer genetics team Refer to Recommendation 5.3 for more information

Post-Testing Genetic Counselling Activities	Baseline	Future	Considerations and Enablers
Provide post-test counselling: • Discuss impacts to current treatment plan (for people in treatment) • Determine surveillance and screening options and intervals • Provide support resources (e.g., information and peer support groups) for patients and their family or caregivers • Provide resources to family members and information to facilitate cascade testing (if applicable)	Genetic counsellor	Genetic counsellor	Not applicable

Post-Testing Genetic Counselling Activities	Baseline	Future	Considerations and Enablers
• Offer instructions to contact the clinic if there is a change in health history			
Write clinic note	Genetic counsellor	Genetic counsellor	Not applicable
Write patient letter	Genetic counsellor/ physician	Genetic counsellor	Genetic counsellor to provide patient letter for majority of cases, with oversight from physician lead (in accordance with institution-specific guidelines) Patients should be directed to patient portal and standard education documents
Send patient letter	Clerk	Clerk	Not applicable
Track and follow-up on test results or other requests	Genetic counsellor	Genetic assistant	Not applicable

Genetic Testing Results Review, Disclosure and Counselling Activities	Baseline	Future	Considerations and Opportunities
Send results to the ordering provider and the genetics team (if the ordering provider was not already on the genetic team)	Molecular geneticist, pathologist	Molecular geneticist, pathologist	Not applicable
Review results to determine interpretation, and to evaluate the need for additional testing and follow-up	Genetic counsellor, medical geneticist, molecular geneticist, pathologist	Genetic counsellor, medical geneticist, molecular geneticist, pathologist	Not applicable
Prepare results letter	Genetic counsellor	Genetic counsellor	Not applicable

Genetic Testing Results Review, Disclosure and Counselling Activities	Baseline	Future	Considerations and Opportunities
Disclose test results through preferred mode of communication (phone, in-person and/or patient portal) – phone and patient portal should be encouraged	Genetic counsellor, physician lead	Genetic counsellor	Not applicable
o Send results letter to referring provider, which should include results, implications and follow-up recommendations	Genetic counsellor/physician lead	Genetic counsellor/physician lead	Not applicable
o Make or initiate referrals	Genetic counsellor/physician lead	Genetic counsellor/physician lead	Not applicable
Facilitate referral or scheduling process for anyone who needs post-test genetic counselling	Genetic counsellor/clerk	Clerk	Not applicable

Work with Providers to Ensure Smooth Transitions for Follow-up Care

Follow-up Activities	Baseline	Future	Considerations/Opportunities
Develop immediate and long-term care plan	Genetic counsellor/physician lead	Genetic counsellor/physician lead	Not applicable
Facilitate referral to other health care providers as appropriate (e.g., peer support services, social work services)	Genetic counsellor/physician lead	Genetic counsellor/physician lead	Not applicable

Patient navigation activities	Genetic counsellor/physician lead	Clinical cancer genetics team or Genetic assistant	Not applicable

Appendix F: Glossary

care transition

The coordination and continuity of care people experience during a change between different health care settings and health care providers during an acute or chronic illness[j]

case preparation

Activities conducted before someone's genetic counselling session to prepare for their unique case (e.g., collecting family and personal health history data, creating pedigrees and risk modelling)

case review

An analysis of someone's personal and family history to ensure that optimum counselling is provided for them and their situation

clinical cancer genetic services

Genetic services specifically related to people with or at risk of cancer, and provided by clinicians with experience in oncology and genetics

clinical cancer genetics team

Interdisciplinary providers working together on someone's case – the team should include a physician lead, genetic counsellor, genetic assistant and clerk who are in close proximity or linked through technology

eConsult

A secure email messaging system that uses the Ontario Telemedicine Network to connect primary care providers with specialists[k]

electronic referral platform (eReferral)
An electronic platform that enables the exchange of patient information between health care providers requesting a service, care and/or support for a patient from another health care provider[l]

extended team

Provide genetic services outside the core services provided by the clinical cancer genetics team – examples of services and providers in this team are provided in Appendix B

gene mutation
A permanent alteration in the DNA sequence that makes up a gene and differs from the same sequence that is found in most people[m]

genetic counselling

The process of advising individuals and families affected by or at risk of genetic disorders to help them understand and adapt to the medical, psychological and familial implications of genetic contributions to disease[n]

genetic services

Provide individuals and families with information about their personal or familial risks of developing a genetic condition and help them better understand and manage these implications. Services typically include management recommendations and options, genetic counselling, initiation of genetic testing, diagnosing genetic conditions, and providing psychosocial counselling and other support services.[o]

[j]https://www.hqontario.ca/Portals/0/documents/qi/health-links/bp-improve-package-transitions-en.pdf
[k] http://ehealthce.ca/eConsult.htm
[l]https://www.ontariomd.ca/documents/lhin%20reports/ontariomd%20-%20provincial%20ereferral%20initiative%20business%20case%20v0.7.pdf
[m]https://ghr.nlm.nih.gov/primer/mutationsanddisorders/genemutation
[n] http://www.genetic-counseling.org/
[o]https://www.mountsinai.on.ca/care/cancer/cancers-we-treat/marvelle-koffler-breast-centre/genetics

genetic testing

A type of medical test that identifies changes in chromosomes, genes or proteins. The results of a genetic test can confirm or rule out a suspected genetic condition or help determine someone's chance of developing or passing on a genetic disorder.[p]

germline genetic testing

Done on cells that do not have cancer to see if someone has a gene mutation that is known to increase the risk of developing cancers and other health problems. This test uses cells, such as blood or skin cells.[q]

hereditary cancer syndrome

A type of inherited disorder that causes a higher-than-normal risk of certain types of cancer. Hereditary cancer syndromes are caused by mutations (changes) in certain genes passed from parents to children. In a hereditary cancer syndrome, certain patterns of cancer may be seen within families.[r]

informed consent

A process of communication between health care providers and their patients to help patients understand the purpose, benefits and potential risks of a health care intervention. Informed consent is also used to get someone's permission before conducting a health care intervention or it can be used for disclosing personal information.[s]

mainstreaming or (oncology-initiated testing)

The process of offering germline genetic testing to eligible people in a cancer clinic, as opposed to the more traditional model of initiating genetic tests through a medical geneticist or genetic counsellor.

medical directive

An order given in advance by a physician or ordering authorizer to enable a provider to perform an ordered procedure under specific conditions without a direct assessment by the physician or authorizer.[t]

model of care

Defines the way health care services are delivered and outlines best practices of care and services for a person, population group or patient cohort as they progress through the stages of a condition, injury or event.[u]

most responsible provider

Refers to the physician or other regulated health care professional who has overall responsibility for directing and coordinating the care and management of a patient at a specific point in time.[v]

pathogenic variant

A genetic alteration that increases someone's susceptibility or predisposition to a certain disease or disorder. When this type of a variant (or mutation) is inherited, development of symptoms is more likely, but not certain.[w]

patient and family advisors

People with experience in the Ontario cancer system. As active participants of the cancer system, patients, families and caregivers can

[p] https://www.cancer.ca/en/cancer-information/cancer-101/what-is-cancer/genes-and-cancer/genetic-testing/?region=on
[q]https://www.seattlechildrens.org/globalassets/documents/for-patients-and-families/pfe/pe2960.pdf
[r]https://www.cancer.gov/publications/dictionaries/cancer-terms/def/hereditary-cancer-syndrome
[s]https://www.medicinenet.com/script/main/art.asp?articlekey=22414
[t]http://www.sickkids.ca/medicaldirectives/101/definition/index.html
[u]https://aci.health.nsw.gov.au/__data/assets/pdf_file/0009/181935/HS13-034_Framework-DevelopMoC_D7.pdf
[v] https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2012/the-most-responsible-physician-a-key-link-in-the-coordination-of-care
[w]https://www.cancer.gov/publications/dictionaries/genetics-dictionary/def/pathogenic-variant

provide unique perspectives and valuable feedback on the standard of care in the system. By partnering with staff and contributing their insights, they provide direct input into policies, programs and practices that affect care and services.[x]

patient education

When a health care professional shares health information with members of the general public so they can learn about specific or general medical topics. The goal of sharing this information is to alter health behaviours or improve health status.[y]

patient journey mapping

A collaborative process that allows participants (e.g., patient and family advisors) to describe their interactions with the health care system and care team during a specific phase of care. Participants focus on identifying the feelings, thoughts and beliefs they experienced or held during those interactions.

patient navigation

When a health care provider guides their patient in overcoming barriers to health care services and provides guidance as their patient moves through the health care system.[z]

patient portal

An electronic platform that allows health care providers to share their patients' personal health care information with them privately.

pedigree

A genetic representation of a family tree that diagrams the inheritance of a trait or disease though several generations. The pedigree shows the relationships between family members and indicates which people express or silently carry the trait in question.[aa]

phenotyping

The process of predicting someone's expression of specific genetic traits and susceptibility to disease using genetic information collected from DNA sequencing.[bb]

physician lead

Any physician with training in clinical genetics who provides clinical advice to genetic counsellors, directs patient care, and provides education or guidance to patients, families and providers. Physician leads may also provide care management for specific populations.

predictive cascade testing

The process of systematic genetic testing of at-risk relatives for a genetic variant. Predictive cascade testing effectively identifies at-risk family members who would benefit from early screening or medical intervention and can potentially lead to early diagnoses and disease prevention.[cc]

primary care provider

Includes most types of health care providers that serve as someone's first point of contact with the health system. Examples of primary care provides are family doctors, general practitioners and nurse practitioners. Primary care providers offer varying types of health care and coordinate their patients' care with other health care providers.[dd]

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[x] https://www.cancercareontario.ca/en/cancer-care-ontario/volunteer-opportunities/about-patient-family-advisors

[y] https://medical-dictionary.thefreedictionary.com/patient+education

[z] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5875656/

[aa] https://www.genome.gov/genetics-glossary/Pedigree

[bb] https://www.merriam-webster.com/dictionary/phenotyping

[cc] https://www.researchgate.net/publication/324607046_How_Can_We_Reach_At-Risk_Relatives_Efforts_to_Enhance_Communication_and_Cascade_Testing_Uptake_a_Mini-Review

[dd] http://www.health.gov.on.ca/en/pro/programs/pcpm/

results disclosure

The process of explaining the outcomes of genetic testing.

results interpretation

The process of explaining the implications of genetic testing results for someone's risk of disease, disease prevention or treatments.

risk assessment / modelling

Used to identify people with a higher cancer risk who may benefit from genetic testing, additional screening or preventive interventions. Using indications from someone's personal and family history, they can be classified as average, increased or high risk.[ee]

team huddle

Short, frequent (i.e., daily) meetings where interdisciplinary health care providers communicate with each other to clinically review their patients.[ff]

[ee] https://www.jax.org/education-and-learning/clinical-and-continuing-education/cancer-resources/cancer-risk-assessment

[ff] https://cepc.ucsf.edu/healthy-huddles

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