



# Canadian College of Medical Geneticists Collège canadien des généticiens médicaux

## Canadian College of Medical Geneticists (CCMG) Points to Consider: Resuming Genetic Services in a Pandemic

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**Abstract:** The present COVID-19 pandemic has created an unprecedented alteration to healthcare in Canada, including the provision of genetic care. With the public health effort to flatten the curve and limit unnecessary exposures, some clinics have moved to virtual care for select populations of patients while triaging and postponing others. Many hospitals have seen a total standstill in all ‘non-urgent’ procedures and indications. While resource-allocation decisions are largely influenced by what is known about the pandemic and current clinical, organizational and government policies, what has emerged are the impact of such systems-level decisions to the care of individual patients and families, particularly in the rare disease world. While perhaps not at the forefront of what most would consider the fight against COVID-19, as genetic services are asked to gradually resume, a roadmap is needed to ensure clinical care decisions for at-risk patients are transparent and equitable, that postponed care is resumed and that patients with or waiting for a genetic diagnosis are not disproportionately affected or abandoned.

The purpose of this document is to highlight the guiding ethical principles and stakeholder considerations in resuming genetic services that may help guide and balance the competing needs going forward of both limiting exposures while maintaining high quality care.

Considerations highlighted are 1) Environment of practice, 2) Nature of consult, 3) Patient factors, 4) Provider factors and 5) Laboratory factors. The intended users are those providing genetic care in a Canadian context with the recognition that there are clinic specific and regional, provincial or territorial variations that will influence decision-making. While specific to the Canadian context, the ethical principles used to guide these decisions would be relevant for consideration in other jurisdictions.

**Introduction:** The present COVID-19 pandemic has created an unprecedented alteration to genetic service delivery in Canada. Physical appointments in a specialty that traditionally relies heavily on comprehensive physical examinations for dysmorphology and sensitive in-person discussions of potentially life-altering information have dramatically changed with the urgency to limit exposures and preserve hospital resources. Human resources in the form of administrative, genetic counsellor, nurses, dieticians, laboratory professional, physician and trainee staffing have sometimes been re-deployed to serve other pandemic needs, leaving genetic clinics short-staffed. Patients have either been transitioned to virtual care, or are being postponed with uncertainty of when the pandemic will resolve. For the purposes of this paper, virtual care is a term used to encompass all forms of digital health that allow healthcare providers to communicate with patients remotely, including telephone calls, secure messaging such as those that are electronic medical records based and teleconferencing solutions that may or may not involve video.[1] Supportive testing such as diagnostic imaging which may aid in phenotyping are not always available. Conventional blood-based laboratory genetic testing is also at a standstill in some centres, largely reserved only for the most urgent of cases.

Like many other specialties at this time, genetics services have been asked to make do with limited resources and enact resource stewardship based on what is considered “urgent” or “essential”. The definition of urgent or essential varies amongst genetic clinics based on the patient populations that they serve, their local capacities as well as provider preferences and patient needs.[2] Not surprisingly, decisions made across clinics are heterogeneous and dependent on multiple factors. Just as tremendous attention has been placed to triage protocols at the front-line of the pandemic, as the situation evolves and ambulatory services are asked to resume, a roadmap is needed to guide this process, keeping in mind the various ethical principles and affected stakeholders, and the continued need to have at least 15% of acute care capacity available to provide COVID-19 care in the hospitals.[3,4] While this resumption of clinical activity should be gradual, it also needs to be flexible to the multiple systems, patient and provider factors at play.

**Purpose:** Like many aspects of the pandemic to date that are based on little or no evidence, there is no prescriptive solution to re-opening of genetic services. Resuming services requires

making decisions that consider trade-offs of certain choices and being able to justify those choices made by using an ethics framework.[5] There is a suggestion to collaborate with providers of the same specialty to determine the best course.[6] The purpose of this document is to highlight the stakeholder considerations and guiding ethical principles in providing the roadmap for resuming of genetic services. Its goal is not to provide direct recommendations, but rather to provide a genetics-specific roadmap to help guide decisions moving forward. The intended users are those providing genetic care in a Canadian context with the recognition that there are clinic-specific and regional, provincial and territorial variations that will influence care. While specific to the Canadian context, the ethical principles to guide these decisions would be relevant for consideration in other jurisdictions.

The following ethical principles should guide service ramp-up:[7,8]

- Transparency: The reasons behind triaging decisions should be open and available
- Reciprocity: A reciprocal obligation exists to those who may be affected by certain decisions
- Reasonableness: Decisions about which care to provide and which to defer should be made on what is thought to be relevant
- Responsive: Decisions should remain flexible and nimble, as new information or data emerges
- Proportionality: Decisions should be proportional to what can be reasonably provided
- Stewardship: Decisions about which care to provide should be guided by patient and public health good
- Accountability: Decisions surrounding resumption of care should be responsible and explainable.
- Inclusive & Fair: The decision to re-start services should ensure the needs of all patients and stakeholders
- Non-maleficence: Care decisions should be grounded in concerns for patient safety and welfare and minimize harm when possible

These procedural and substantive values are in no particular hierarchical order but, when carefully applied to decision-making, can aid in prioritization.

**Considerations:**

The following decision-making considerations will be discussed and, where appropriate, the salient ethical principle identified.

- A. Environment of Practice
- B. Nature of Consult
- C. Patient Factors
- D. Provider Factors
- E. Laboratory Factors

**A. Environment of Practice**

**Current state:** The practice environment within a clinic is influenced by a multitude of factors. Some of these are external to the clinic, based on provincial/territorial public health policies while other organizational factors are specific to the hospital or institution. The local or regional prevalence of the virus and the availability of personal protective equipment (PPE) certainly influences the above. Currently, with clinicians re-deployed, there may be fewer staff to cover the incoming results ordered by colleagues and to deal with emergent referrals.

**Points to consider:**

1. Provincial healthcare systems - Will dictate the timing of resuming services in the province/territory as well as what support is in place (e.g. telemedicine) to provide ongoing care going forward.[9] (Reasonableness)
2. Catchment area - Whether the genetics service is a local, regional or tertiary care program affects the catchment area and thus the numbers of referrals waiting for an appointment. In resuming from a pandemic, consideration can be made to coordinate

with other centres with limited resources such as northern clinics or clinics with redeployed staff, which could benefit patients provincially. (Inclusive & Fair)

3. Hospital policy - Organizational policies may dictate when patients can be seen in-person and whether they can bring family members. If there are waves of COVID-19, hospital decisions may affect further staffing and redeployment decisions (Responsive)
4. Clinic factors – In order to maintain physical distancing, minimizing patients in the waiting rooms and providing adequate personal protective equipment continue to be required to minimize COVID-19 transmission.[2,3,10,11] Staggering staffing to maintain social distancing and cleaning protocols while ensuring coverage in the office is also a recommended consideration.[2] (Responsive) Availability of PPE is necessary. (Reciprocity).
5. Availability of Electronic Medical Records (EMR) - Where clinics are paper-based rather than EMR-based, would determine the ease of being able to work remotely or not. The ability to have some staff work from home increases the ability to physically distance in the clinic. (Proportionality)
6. Remuneration model - The way providers are remunerated, including the availability of virtual care billing codes, may affect the number of patient appointments available in the short term and how future models of care can be maintained. (Accountable)

## **B. Nature of Consult**

**Current state:** While some clinics are continuing to see urgent patients in person, others are being seen virtually. Still others are being postponed based on the nature of the consultation, with thoughts that their care can be safely delayed. These triage decisions currently involve considerable heterogeneity and create new trade-offs for patients. For example, in some areas, patients who would normally be seen to assess their risks for hereditary cancers are being deferred. Where they are being seen, provincial programs for cancer screening and surveillance may be postponed, leading to additional barriers to care. In other areas, the traditional ‘phenotype first’ approach is also changing, with some decisions to pursue further genetic testing without the ancillary tests one might have pursued prior to the pandemic.

## Points to consider:

1. Models of care - There may be a need to reconsider models of care, particularly in a multidisciplinary setting to decide how patients may be best seen. This may involve consideration of hybrid models of virtual and in-person care that may not have been utilized prior to the COVID-19 pandemic and working together to determine the best team-based approach. The referral indication may determine whether a physical examination by a geneticist is needed or can be deferred until initial investigations return. Consideration can be made for an initial virtual visit, waiting until an in-person assessment is possible, or a hybrid solution.[12] Consideration should also be made in these models of care for patients requiring frequent follow-up (Responsive, Inclusive & Fair)
2. Priority - Wait lists could be reviewed to ensure patients of higher priority receive necessary attention. Harm could be minimized so that those at higher risk of morbidity/mortality would have shorter delays in processing versus those at lower risk. There needs to be a careful balance between new referrals and follow-ups, particularly for follow-ups of known conditions where management is likely not going to be impacted. (Inclusive & Fair)
  - a. Prenatal
    - i. Given the timeframe of a pregnancy, timely access to genetic services should be considered urgent in our field. Access is also needed for all the supportive services including access to diagnostic prenatal testing, tertiary care imaging, maternal fetal medicine specialists and providers of pregnancy options. (Non-maleficence)
    - i. While routine soft marker or other screen-positive prenatal counselling can be done virtually, offering in-person assessments for severe congenital anomalies or significant discussions ought to be considered.
    - ii. Consideration could be made for continuing pre-conception counselling for at-risk couples, which may be ideally suited to virtual care. Access to early information and discussions on pregnancy risk may, depending on

the values of the family, prevent pressured and emergent reproductive decisions. Carrier screening could be carefully considered based on whether the information would change management for couples. (Non-maleficence)

b. Pediatric

- i. Inpatient genetic consultations ought to continue. These can be done in person or virtually, where appropriate. Telephone advice for first tier testing could also be utilized as a model of care.
- ii. Priority for new referrals could be given to babies or young children, those with new clinical or molecular diagnoses or where there is significant parental anxiety.

c. Metabolic

- i. Urgent metabolic presentations, as well as those requiring in-person therapies or examinations, should continue to be seen. Given the risks with COVID-19, ensuring compliance with therapies and diet are equally important to prevent decompensation. (Proportionality)
- ii. If possible, virtual care can be considered to maintain health and prevent decompensation and this should be prioritized.

d. Adult and Cancer

- i. Individuals in the end of life may benefit from prioritized care that could be conducted virtually as a definitive diagnosis in an affected individual has implications for screening and management of at-risk family members (Non-maleficence)
- ii. Telephone counselling for known conditions has been done prior to the pandemic in certain settings and could potentially continue upon resuming services based on political and hospital policies. This may decrease the projected backlog of cases that need to be re-booked.

3. Other investigations - The availability of non-laboratory services from diagnostic imaging to home care need be factored in. Drug shortages, particularly in the metabolic realm, should be considered. (Stewardship)

### **C. Patient factors**

**Current state:** The vast majority of our patients and families are currently being seen virtually, and while this modality may work for a majority, patients whose first language is not English or who do not have access to or comfort with reliable technology as well as patients with hearing or vision difficulties, may not be receiving optimal care. Currently, patients seen in-person are potentially more at risk to contract COVID-19 by coming to the hospital, often without the support of their partner or family member due to the no visitor policy of many hospitals, though this will continue to evolve with the prevalence of the virus. Decisions on who to see virtually and who to see in-person are ongoing.

#### **Points to consider:**

1. Access to internet/technology - For effective virtual care, the patient must have access to reliable and stable home telephone or internet connection with an appropriate computer, tablet or phone. Those who cannot afford or do not have the digital literacy for video calls cannot access the visual aids in real time that are often important in genetic counselling. Furthermore, genetic care providers may be missing psychosocial cues during telephone consultations that may affect the patient's experience and need to be addressed. Consideration could be made to determine the most ideal method for delivery of care.[4,13] (Inclusive & Fair)
2. Communication - Translation solutions for virtual care should also be included wherever needed. Consideration could also be given in the context of visitor restrictions for family members who may have interpreted previously. Other forms of communication with patients, such as asynchronous secure messaging, could be explored. (Inclusive & Fair)

3. Level of risk– Given that certain comorbidities increase the chance of morbidity and mortality from COVID-19,[14] certain patients may benefit from the continued ability to be seen virtually, even as ramp-up occurs. (Non-maleficence)
4. Geography and cost of travel – Patients who live further from genetics clinics may continue to benefit from being seen virtually in order to have access to their specialists. (Inclusive and Fair) There are costs of travel to an in-person appointment, such as time off work, cost of parking, meals and in some cases, accommodations. By continuing with the possibility of virtual care, these costs could be decreased for patients. (Reasonable)
5. Anxiety/coping and ability to wait – Many patients may have been waiting a long time for their genetics assessment. They may either have significant anxiety in wanting to be seen as soon as possible or in contrast, would be more comfortable waiting until it is safer to be seen. Further contextual factors such as working from home and childcare needs and other social determinants of health may affect the ability to be seen at present. Accommodation of patient’s psychological needs and preferences, along with other contextual factors, could be considered to ensure equity. (Responsive, Inclusive & Fair).

#### **D. Provider factors**

**Current state:** In this unprecedented time, clinicians - like patients - have had varying reactions to and acceptance of the change in their day-to-day roles. Not surprisingly, there is currently great heterogeneity as to how providers are working, including those who may have volunteered for other COVID-19 efforts.

#### **Points to consider:**

1. Duty to care - While a duty to care and a fiduciary responsibility to patients exists for clinicians, how to enact that duty and balance that duty between current and future, COVID and non-COVID patients, particularly when patients are not able to be seen, requires ongoing discussion.[15] (Stewardship)

2. Level of risk – The providers themselves may have reservations given their own underlying health conditions or those of close family contacts in seeing patients in-person who may increase their risk of infection. Given that many genetic services are group-based, discussion amongst providers in the clinic could be considered as to who would be best to see the patient in-person and who may join virtually.[16] Compliance with infection prevention and control (IPAC) procedures access to sufficient PPE are also needed to mitigate infection risks.[2] (Reciprocity)
3. Comfort with technology – Some providers are more comfortable with virtual care than others and this may influence their decisions to see patients in-person or virtually. Education and skill-building to address the technological aspects of this could be considered. Providers should also continue to consider the standard of care when offering virtual visits and the limitations this type of care may place.
4. Ability to work from home – Some centres are enabling providers to work from home. As services start to resume at different times, child-care needs and the provisions of appropriate support will be a consideration for providers with family commitments. Privacy and confidentiality need to be maintained when working from home and require the appropriate space, resources and tools to do this.[17] (Transparency)
5. Burnout/Division of clinical responsibilities – Providers should be mindful of downloading aspects of care to other physicians/members of healthcare team. Clear communication is required if aspects of care are to be distributed with a recognition that other providers are under similar constraints due to COVID-19. Other factors that contribute to provider well-being could be monitored and addressed. (Reciprocity)

#### **E. Laboratory factors**

**Current state:** Many patients referred to clinical genetics will require some type of confirmatory test. With decreased volumes, genetic laboratories may be getting through their backlog of cases or may have redirected their staffing or reagents to other COVID efforts. Many out-of-country genetic testing laboratories have mobilized during this time to offer at home

buccal kits or other convenient sampling. Provinces already differed regarding their approval process and funding for out of country testing and this may have been further exacerbated by COVID-19.

**Points to consider:**

1. Urgency of genetic testing - Priority should continue to be given based on the urgency of the test. These may include but are not limited to prenatal testing, work up for suspected metabolic disorders, newborns with anomalies and diagnostic testing for conditions where there may be a change in management. Cascade testing of family members to sort out the significance of variants of uncertain significance could be carefully reviewed considering what information the testing results will provide if resources continue to be constrained. (Reasonable)
2. Need for bloodwork - Practical considerations, such as whether a patient has DNA banked already and thus would not have to come in for bloodwork, should not be used in isolation in deciding which patients can be seen. In a similar light, the risks and benefits of singleton over trio testing, such as in trio whole exome sequencing, in terms of number of exposures and/or health care visits needed for blood draws should be considered. (Non-maleficence)
3. Availability of lab testing/capacity - When it is safe to resume non-urgent blood draws, there may be a backlog given that there will be many patients needing to be tested and lab availability needs to be considered. Consideration, where appropriate, of buccal swabs, blood spots or home-based kits may mitigate some of the risks associated with presenting for bloodwork is a unique advantage to Genetics as a specialty in being able to offer a safe option to patients. (Responsive)
4. Funding of genetic testing – There may be short-term consequences in the approval processes for and turnaround times of out of country testing because of COVID-19. In the long-term, the pandemic may further disrupt approval times and/or decrease funding for out of country testing if there is reallocation of healthcare funding. (Proportionality, Stewardship)

## Conclusions

While most genetic diagnoses may not be comparable to other urgencies in healthcare that can be immediately lifesaving (certain metabolic diagnoses of course a notable exception) these diagnoses can have significant impacts on health and may carry significant value to patients and families. Beyond mere information, there continues to be a utility in genetic testing for prevention of disease and maintenance of health, so long as the healthcare system is able to support the downstream implications of a test result e.g. screening, prophylactic surgeries, developmental services, etc. Thus, genetic services need to be situated in the broader health care context especially amid a pandemic - where resources may be limited - and a relational notion of utility adopted.

This document serves to highlight key points, ethical principles and identified stakeholders to consider in the resumption of genetic services. The environment of practice, nature of consult, patient factors, provider factors and laboratory factors will likely differ regionally and thus this document serves to highlight those factors requiring consideration as genetic practices resume. Which patients are seen and when will require a careful calculus of all of the above considerations and likely others as the landscape evolves in time in order to maintain the delivery of high-quality genetic care. It will also be important to follow the unintended consequence of this pandemic in already marginalized and disadvantaged groups, such as those with suspected underlying genetic conditions.

The road forward for resuming genetic services should be gradual, flexible and responsive and include:

- A regional approach to providing patient care where decisions are made through a concerted effort across all stakeholders.
- A consideration of where a patient's genetic diagnosis may be situated within the broader resource-constrained healthcare setting.
- New tools to triage patients and identify those that are suitable for virtual care that recognize patient factors as outlined above.

- The continued use technology to deliver care considering the various patient and provider factors at play.
- An understanding that COVID-19 has changed the way genetics is being practiced. The virtual visits, phenotype versus genotype first and lack of physical examinations have prompted a new way of practicing genetics such as thinking critically about existing triage criteria, necessitating a potential second visit for physical examination, or considering patient factors like their technological capabilities. This new model needs to be formally evaluated but may serve as an opportunity to build robust long-term solutions.
- A capturing of the downstream implications of factors that may delay diagnoses and cause fragmented care as services resume.

It is possible that with careful and thoughtful consideration of the above issues that the road forward is in fact exactly what was needed even before the pandemic: an inclusive, accessible and accountable path for accessing genetic care in Canada.

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**Footnotes:**

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