

## POSITION STATEMENT

# Canadian College of Medical Geneticists (CCMG) points to consider: resuming genetic services in a pandemic—a summary

Lauren Chad ,<sup>1,2,3</sup> Angelika J Dawson,<sup>1,4</sup> Elaine Suk-Ying Goh <sup>1,5</sup>

<sup>1</sup>Education, Ethics and Public Policy Committee, Canadian College of Medical Geneticists, Kingston, Ontario, Canada

<sup>2</sup>Division of Clinical and Metabolic Genetics, The Hospital for Sick Children, Toronto, Ontario, Canada

<sup>3</sup>Department of Bioethics, The Hospital for Sick Children, Toronto, Ontario, Canada

<sup>4</sup>Genomics (Cytogenetics), Diagnostic Services, Shared Health Manitoba, Winnipeg, Manitoba, Canada

<sup>5</sup>Laboratory Medicine and Genetics, Trillium Health Partners, Mississauga, Ontario, Canada

## Correspondence to

Dr Elaine Suk-Ying Goh, Laboratory Medicine and Genetics, Trillium Health Partners, Mississauga, ON L5M 2N1, Canada; elaine.goh@thp.ca

Received 10 August 2020  
Revised 24 October 2020  
Accepted 27 October 2020

## ABSTRACT

The COVID-19 pandemic has disrupted the provision of genetic care in Canada. With the public health effort to flatten the curve, many clinics have moved to virtual care for select populations of patients while triaging and postponing others. 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 to help guide 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 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 COVID-19 pandemic has disrupted genetic service delivery in Canada, a specialty that traditionally relies on comprehensive dysmorphology examinations and sensitive in-person discussions. As part of the pandemic response, many clinics moved to virtual care, allowing healthcare providers to communicate with patients remotely by telephone, secure messaging and videoconferencing.<sup>1</sup> Others continued to see only what is considered ‘urgent’, though this definition varies among clinics.<sup>2</sup> Not surprisingly, the traditional ‘phenotype-first’ approach has also changed, with other pandemic-related limitations in ancillary testing. As ambulatory services begin to resume, an opportunity to rethink care decisions has emerged, so that at-risk patients do not face additional barriers to genetic care.

## PURPOSE

The purpose of this document is to highlight the guiding ethical principles and stakeholder considerations in resuming genetic services. Its goal is not to provide direct recommendations, but rather a

genetics-specific roadmap to help guide decisions. The intended users are those providing genetic care in a Canadian context realising that there are evolving public health guidelines and clinic-specific and regional variations that will continue to influence care.

## POINTS TO CONSIDER

Table 1 lists, in no particular order, the ethical principles that when carefully applied to decision-making, can aid in prioritisation.<sup>3,4</sup> Table 2 provides examples of changes prompted by the pandemic leading to shifts in medical genetics clinical principles and practices.

The following are considerations:

### 1. Environment of practice

- Healthcare systems: will dictate the timing of resuming services as well as what ongoing support is in place (eg, virtual care, availability of personal protective equipment (PPE)).<sup>5</sup> (Reasonableness)
- Catchment area: coordination with local, regional or tertiary centres with limited resources or long wait lists could benefit patients provincially. (Inclusive and fair)
- Hospital policy: hospital decisions may affect further staffing and redeployment decisions, as well as timing of in-person visits and visitor restrictions. (Responsive)
- Clinic factors: staggering staffing to maintain social distancing and minimise patients in waiting rooms is a recommended consideration.<sup>2</sup> (Responsive)
- Availability of electronic medical records (EMR): EMR-based charts increase the ease of being able to work remotely. (Proportionality)
- Remuneration model: provider remuneration, including the availability of virtual care billing codes, will affect how models of care can be maintained. (Accountable)

### 2. Nature of consult

- Models of care: hybrid models of virtual and in-person care may be needed, including decisions to defer physical examinations, where appropriate, until initial investigations return.<sup>6</sup> Consideration should also be made for patients requiring frequent follow-up and the optimal multidisciplinary, team-based approach. (Responsive, Inclusive and fair)



© Author(s) (or their employer(s)) 2020. No commercial re-use. See rights and permissions. Published by BMJ.

**To cite:** Chad L, Dawson AJ, Goh ES-Y. *J Med Genet* Epub ahead of print: [please include Day Month Year]. doi:10.1136/jmedgenet-2020-107394

**Table 1** Ethical principles to guide resumption of genetic services<sup>3,4</sup>

Ethical principle	Description
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 emerge.
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 and fair	The decision to restart 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 minimise harm when possible.

- b. Priority: wait lists could be reviewed to ensure patients of higher priority receive necessary attention. A careful balance between new referrals and follow-ups is needed, particularly for follow-ups of known conditions where management is unlikely impacted. (Inclusive and fair, Non-maleficence)
    - Prenatal: timely access to prenatal testing, imaging and specialty care should be considered essential. While preconception, soft marker or other screen-positive counselling can be done virtually, in-person assessments for severe congenital anomalies or significant discussions ought to be considered. Carrier screening could be carefully considered based on whether this information would change management.
    - Paediatric: inpatient genetic consultations ought to continue, either in person or virtually. Telephone advice for first-tier testing could also be used. 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.
    - Metabolic: urgent metabolic presentations, as well as those requiring in-person therapies or assessments, should continue to be seen. If possible, virtual care to maintain health and prevent decompensation should be prioritised.
    - Adult and cancer: individuals in the end of life may benefit from virtual prioritised care as a definitive diagnosis in an affected individual has implications for at-risk family members.
  - c. Other services: the availability of non-laboratory services from diagnostic imaging to developmental support and drug shortages need to be considered. (Stewardship)
3. Patient factors
- a. Access to technology: for effective virtual care, the patient must have access to and comfort with reliable telephone or internet connection with an appropriate device. Those who do not have the digital literacy or access to video calls may not be able to benefit from visual aids important in genetic counselling.<sup>7,8</sup> (Inclusive and fair)
  - b. Communication: translation solutions for virtual care, exceptions to visitor restrictions or in-person visits for individuals with hearing, vision or other difficulties should be included wherever needed. Other forms of communication with patients, such as asynchronous secure messaging, could be explored. (Inclusive and fair)
  - c. Level of risk: certain patients may benefit from the continued ability to be seen virtually, even as ramp-up occurs, to decrease COVID-related morbidity and mortality. (Non-maleficence)
  - d. Geography: as there are costs of travel to an in-person appointment, consideration should be made for virtual care when possible. (Reasonable)
  - e. Ability to wait: patients may be anxious to be seen or in contrast, may wish to defer their appointment. Other

**Table 2** Examples of significant changes prompted by the pandemic leading to shifts in clinical principles and practices of medical genetics

	Prepandemic genetic service delivery	Pandemic-related changes	Shifts in clinical principles and practices moving forward
1. Environment of practice	Patients physically seen in clinic based on geographic factors.	Increased use and availability of virtual care: many patients now able to be 'seen' in their home environments without the need to travel to clinic.	Coordination at the local or regional level could be considered to improve access to genetic care.
2. Nature of consult	In-person, comprehensive history taking and dysmorphology examinations that often require measurements or specific manoeuvres and sensitive in-person discussions.	Increased use and availability of virtual care. Pandemic-related limitations in ancillary testing like physical examination, imaging or specialised laboratory testing.	Shifting from a 'phenotype-first' approach may allow for new models of in-person, virtual or hybrid care where genetic testing may be offered earlier than in traditional models.
3. Patient factors	Patients had to take time off work to travel and pay for parking and childcare to attend in-person visits.	Public health guidelines to restrict non-essential visits. Increased use and availability of virtual care. Centring practices on protecting safety of patients.	Accommodation of patient preferences for the location and timing of care, particularly for individuals who may belong to a marginalised or disadvantaged group, may be increasingly important to consider.
4. Provider factors	Physicians, genetic counsellors and laboratory personnel traditionally worked in hospitals without the ability to work from home.	Public health guidelines to restrict non-essential visits. Availability and support to work remotely. Centring practices on protecting safety of providers and preserving PPE.	Consideration of leveraging the use of virtual care and remote working environments may balance provider needs and safety.
5. Laboratory factors	Molecular genetic testing primarily done on a blood sample.	Increased use of saliva and buccal swabs to decrease need to have physical contact for phlebotomy.	Incorporating more non-invasive and convenient sample collection may be a safe and welcome shift for some types of genetic testing.

PPE, personal protective equipment.

factors, such as working from home, childcare needs and other social determinants of health, may affect the ability to be seen. Accommodation of patient's psychological needs and preferences, along with other contextual factors, should be considered. (Responsive, Inclusive and fair)

#### 4. Provider factors

- a. Duty to care: while a duty to care and a fiduciary responsibility to patients exist for clinicians, how to enact and balance that duty between current and future patients with and without COVID-19 requires an ongoing discussion.<sup>9</sup> (Stewardship)
- b. Level of risk: discussion among clinic colleagues could be considered as to who would be best to see patients in person, taking into account colleagues with health conditions in themselves or close family members.<sup>10</sup> Compliance with infection prevention and control procedures access to appropriate PPE is also needed.<sup>2</sup> (Reciprocity)
- c. Comfort with technology: providers' comfort with virtual care may influence their decisions to see patients virtually. Education and skill building to address these competencies 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.
- d. Ability to work from home: childcare 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.<sup>11</sup> (Transparency)
- e. Burn-out and division of clinical responsibilities: providers should be mindful of downloading aspects of care to other providers under similar COVID-19 constraints. Provider well-being should be monitored and addressed. (Reciprocity)

#### 5. Laboratory factors

- a. Urgency: priority should continue to be given based on the urgency of the test, such as 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 variant significance could be carefully reviewed for their informational value. (Reasonable)
- b. Need: practical considerations, such as whether a patient has DNA already banked, should not be used in isolation in deciding which patients can be seen. Similarly, the risks and benefits of singleton over trio testing in limiting exposures should be balanced with diagnostic yield. Where appropriate, convenient sampling with home buccal kits or blood spots that mitigate exposure risk may be a safe alternative. (Non-maleficence)
- c. Funding of genetic testing: there may continue to be differences in the approval processes for and turnaround times of out-of-country testing because of COVID-19. In the long term, the pandemic may exacerbate funding differences and will require ongoing monitoring. (Proportionality, Stewardship)

resume. Care decisions will require a careful calculus of all of the above considerations. While most genetic diagnoses may not be comparable to other urgencies in healthcare (certain metabolic diagnoses being a notable exception), these diagnoses can have significant impacts on health and may carry significant value to patients and families, so long as the healthcare system is able to support their downstream effects.

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

- ▶ A regional approach to providing 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 identify patients who can be seen virtually, and the continued use of technology to deliver care, recognising patient and provider factors.
- ▶ An understanding that COVID-19 has changed the way genetics is being practised. The virtual visits and 'genotype-first' approaches prompt new ways of thinking critically about how to offer the best in-person, virtual or hybrid care. These new models require evaluation but may serve as an opportunity to build robust long-term solutions.
- ▶ A capturing of the downstream implications that may delay diagnoses and cause fragmented care as services resume, realising patients with suspected underlying genetic conditions may already belong to a marginalised or disadvantaged group.

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

**Acknowledgements** The authors wish to thank Randi Zlotnik Shaul for feedback on the manuscript. They would also like to acknowledge the critical review and feedback from the boards of the Canadian College of Medical Geneticists, Canadian Association of Genetic Counsellors, the Education, Ethics and Public Policy, and Clinical Practice Committees, especially and not limited to Mary Ann Thomas, Isabelle DeBie, Alessandra Cumming, Melanie Care, Ioannis Trakadis, Leanne Mercer and Joanna Lazier.

**Contributors** The conception of the document was by LC and ESYG with additional contribution to the design by AJD. Drafting, revising and final approval of the work were done by all authors. All authors agree to be accountable for all aspects of the work.

**Funding** The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

**Competing interests** None declared.

**Patient consent for publication** Not required.

**Ethics approval** The extended version of this document was reviewed by the Canadian College of Medical Geneticists (CCMG) Education, Ethics and Public Policy, and Clinical Practice Committees and approved by the boards of the CCMG and the Canadian Association of Genetic Counsellors (CAGC).

**Provenance and peer review** Not commissioned; externally peer reviewed.

This article is made freely available for use in accordance with BMJ's website terms and conditions for the duration of the covid-19 pandemic or until otherwise determined by BMJ. You may use, download and print the article for any lawful, non-commercial purpose (including text and data mining) provided that all copyright notices and trade marks are retained.

#### ORCID iDs

Lauren Chad <http://orcid.org/0000-0003-0468-6663>

Elaine Suk-Ying Goh <http://orcid.org/0000-0002-2477-1665>

#### REFERENCES

- 1 College of Physicians and Surgeons of Alberta. Advice to the profession: COVID-19: virtual care. Available: [http://www.cpsa.ca/wp-content/uploads/2020/03/AP\\_COVID-19-Virtual-Care.pdf](http://www.cpsa.ca/wp-content/uploads/2020/03/AP_COVID-19-Virtual-Care.pdf) [Accessed 11 Jul 2020].

#### CONCLUSIONS

This document serves to highlight key points, ethical principles and identified stakeholders to consider when genetic services

- 2 Ontario Medical Association. *Principles for the re-introduction of deferred services*, 2020.
- 3 Upshur REG, Faith K, Gibson JL, Thompson AK, Tracy CS, Wilson K, Singer PA. *Stand on guard for thee. ethical considerations in preparedness planning for pandemic influenza*. University of Toronto Joint Centre for Bioethics, 2005.
- 4 Ontario Health. *A measured approach to planning for surgeries and procedures during the COVID-19 pandemic*, 2020.
- 5 Royal College of Physicians and Surgeons of Canada. *Telemedicine and virtual care guidelines (and other clinical resources for COVID-19)*. Available: <http://www.royalcollege.ca/rcsite/documents/about/covid-19-resources-telemedicine-virtual-care-e> [Accessed 31 May 2020].
- 6 Collège des Médecins Du Quebec. *Les téléconsultations réalisées PAR les Médecins durant La pandémie de COVID-19*. Available: <http://www.cmq.org/publications-pdf/p-1-2020-03-31-fr-les-teleconsultations-realisees-par-les-medecins-durant-la-pandemie-de-covid-19.pdf> [Accessed 11 Jul 2020].
- 7 Health O. *Recommendations for regional health care delivery during the COVID-19 pandemic: outpatient care, primary care and home and community care*, 2020.
- 8 College of Physicians and Surgeons of Saskatchewan. *Practical information for virtual visits*. Available: <https://www.cps.sk.ca/iMIS/Documents/PANDEMIC/COVID-19/2020.05.01%20Practical%20guidance%20for%20Virtual%20Care%20delivery%20during%20the%20COVID-19%20pandemic.pdf> [Accessed 11 Jul 2020].
- 9 Canadian Medical Protective Association. *Duties and responsibilities: scarce resources: caring for patients during COVID-19*, 2020. Available: <https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2020/scarce-resources-caring-for-patients-during-covid-19> [Accessed 4 Jun 2020].
- 10 College of Physicians and Surgeons of Manitoba. *Providing medical care during COVID-19*, 2020. Available: <https://cpsm.mb.ca/assets/COVID19/Medical%20Care%202020%2004%2006.pdf> [Accessed 11 Jul 2020].
- 11 Canadian Medical Protective Association. (a), *COVID-19 hub advice, support and medical-legal information, frequently asked questions, can I use virtual care to see patients during the COVID-19 outbreak? if so, what products should I use?* Available: <https://www.cmpa-acpm.ca/en/covid19> [Accessed 31 May 2020].