

SPECIAL ISSUE

Genetic counseling research and COVID-19: A lesson in resiliency

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Abstract

GenCOUNSEL is the largest genetic counseling research grant awarded to date and brings together experts in genetic counseling, genomics, law and policy, health services implementation, and health economics research. It is the first project of its kind to examine the genetic counseling issues associated with the clinical implementation of genome-wide sequencing (exome and genome sequencing). GenCOUNSEL is a Canadian-based, multi-method research study that takes place over a variety of sites, including non-clinical, clinical, and laboratory research sites and includes the training of undergraduate and graduate students. The COVID-19 pandemic will likely have a lasting impact on genetic counseling service delivery, research, and training. Almost every aspect of the GenCOUNSEL research project has been impacted by the COVID-19 pandemic. Here we describe how our research recruitment strategies, methods, resource allocation, and training capacity have been affected. We discuss ways that we have adapted to the pandemic including revision of our research methods and work to understand the barriers in order to optimize opportunities. We finish with take-home messages to fellow researchers highlighting the importance of resiliency in genetic counseling research.

KEYWORDS

clinical research, COVID-19 response, genetic counseling, genome-wide sequencing

1 | BACKGROUND

Genome-wide sequencing (GWS; genome and exome sequencing) is becoming increasingly available in clinical settings and current guidelines consider genetic counseling an essential part of the implementation of GWS (Bowdin et al., 2016; Boycott et al., 2015; Elliott & Friedman, 2018; Green et al., 2013; Knoppers et al., 2015; Matthijs et al., 2016). As GWS becomes more broadly integrated in clinical care, there is the requirement for high-quality evidence about all areas of implementation to ensure that service delivery of GWS and genetic counseling is patient-centered, sustainable for the healthcare system, and evidence-based in order to maximize the benefits that patients and families receive. GenCOUNSEL

is a large-scale research project based in Canada that brings together experts in genetic counseling, genomics, law and policy, health services implementation and health economics research. It is the first project of this scale to examine the genetic and genomic counseling issues associated with the clinical implementation of GWS. GenCOUNSEL has four main pillars of research, each with specific aims and goals. Pillar one evaluates the *profession* with the goal of understanding the current and future need for genetic and genomic healthcare providers through the creation of workforce models to estimate the need for services and the workforce supply. The second pillar is *programs* which investigates and develops best practices for delivery of genetic and genomic counseling. The third pillar is *practice* which aims to improve access to genetic and

genomic counseling, especially for underserved patient populations, and the fourth is *policy* with the goal to develop a framework for the legal recognition of genetic counselors in Canada (Figure 1).

This 4.2-million-dollar (CAD) project is funded by Genome Canada, Genome BC, Genome Quebec, Canadian Institutes of Health Research (CIHR), BC Children's Hospital Foundation, BC Women's Hospital and Health Centre Foundation, and the Provincial Health Services Authority, and it is being conducted through the University of British Columbia and McGill University. The project launched in 2018 and was initially intended to be completed by mid-2022. Our multidisciplinary research team includes genetic counselors, clinical geneticists, health economists, decision scientists, ethics, legal and policy specialists, and other researchers across Canada and internationally, with collaborators in Europe and Australia. Our main research settings include clinical laboratory (laboratories involved in processing requests for genetic testing) and dry laboratory (computer/office-based environments where research is conducted) settings at the University of British Columbia, BC Children's and Women's Hospital, McGill University, Montreal University Health Centre, and The Cool Aid Clinic in Victoria, British Columbia.

The majority of our research is taking place within two Canadian provinces, British Columbia and Quebec. Both provinces have had varying degrees of work and travel restrictions in place since March 2020. In both provinces, there was an abrupt transition to remote work in mid-March 2020. In British Columbia, there was some limited return to in-person clinical research in July 2020. The sites in Quebec have still been considered high-risk for infection transmission since March 2020 and by May 2021 there had been essentially no return to in-person research.

The COVID-19 pandemic has fundamentally changed the ways that genetic and genomic counseling research, training, and service provision are conducted, and will likely continue. The majority of available literature on this topic so far has focused on remote provision of clinical services (Pagliuzzi et al., 2020; Shannon et al., 2020; Shur et al., 2020) and workforce issues (Bergstrom et al., 2020). The GenCOUNSEL research study is unique because it contains diverse research goals and a multidisciplinary research team, across many different research settings. We outline some of the challenges that we have faced and solutions that we have implemented in hopes that this can add to our understanding of the impacts of the COVID-19 pandemic on the field of genetic counseling. We describe how our research recruitment strategies, methods, resource allocation, and training capacity have been affected and highlight ways we have adapted our aims and methods. We discuss how virtual research has both created and eliminated barriers for participants and, finally, the importance of resiliency in genetic counseling research.

2 | OVERVIEW OF GENCOUNSEL PROJECT AND ELEMENTS IMPACTED BY COVID-19

As described above, the GenCOUNSEL study is comprised of a number of pillars, each with sub-activities. In this section, we outline

What is known about this topic?

The COVID-19 pandemic has affected and continues to impact many aspects of the genetic counseling field. There have been a limited number of publications on changes in service provision to allow for the delivery of genetic counseling through telehealth and the workforce posed by remote work such as billing and licensure issues. Currently, there is very little known about the specific impacts that the pandemic has had on research studies and training capacity. To our knowledge, there are currently no published studies highlighting the impacts of COVID-19 on genetic counseling research in Canada.

What this paper adds to the topic

This commentary recounts the experiences of GenCOUNSEL, a large-scale, multi-method Canadian-based research project that is aiming to optimize the implementation of genetic counseling and genome-wide sequencing. Almost every aspect of our research has been impacted by the COVID-19 pandemic. We describe our experiences below and how we have adapted to these challenges.

some of the key areas in which our research has been impacted by the COVID-19 pandemic.

2.1 | Pillar one: profession

This element of the work is primarily focused on creating macro-economic models to estimate the current and future need for genetic services and the clinical workforce required to provide those services. The two sub-activities within this pillar that were most impacted by the COVID-19 pandemic were part of an environmental scan to help inform model development. The first was an online Delphi panel to survey Canadian genetics professionals from across Canada about their perspectives about the future of genetic services. The second was in-person stakeholder focus groups, where the purpose was to obtain feedback from multiple stakeholders on the validity and usability of our workforce models.

2.2 | Pillar two: programs

There are two main goals of this pillar of research, both of which were impacted by the COVID-19 pandemic. The first is to explore the impact of involving a genetic counselor in genetic and genomic test selection to reduce inefficiencies and inappropriate test ordering, and the second is to explore patient experiences with genome-wide sequencing to improve patient outcomes. To achieve the first

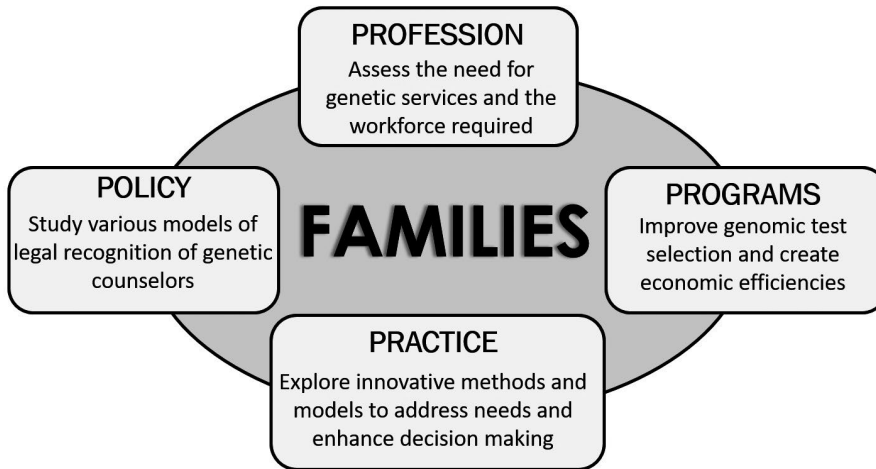


FIGURE 1 Overview of the GenCOUNSEL Research Study. The GenCOUNSEL project is comprised of four main research pillars: Profession, Programs, Practice, and Policy. All of this research is done with the goal of increasing access to genetic and genomic services for the families who need it

goal, we are embedding a genetic counselor into two different clinical laboratory settings in two Canadian provinces (BC and Quebec) to review requests that have been submitted for publicly funded genetic testing. In Canada, some genetic and genomic testing is funded by the public healthcare system if there is sufficient evidence for medical necessity, and each province has a distinct system in place to assess genetic testing requests. Our study will investigate the impact of integrating a genetic counselor into this review process. The second goal of this research is being met through multi-method research studies with different users of genome-wide sequencing in different clinical capacities. To date, this has included qualitative interviews with individuals who have experience with rapid genome sequencing in the neonatal intensive care unit, individuals who have received incidental findings from genome-wide sequencing, and adolescents who are affected with a genetic condition in addition to their unaffected siblings.

2.3 | Pillar three: practice

This pillar of research also has two main sub-activities that have been impacted by the COVID-19 pandemic. The first is the implementation of an electronic decision aid that was previously developed by some of the GenCOUNSEL team (DECIDE; Decision-aid & E-Counseling for Inherited Disorder Evaluation; Adam et al., 2018; Birch et al., 2016) in a variety of clinical settings where patients are undergoing clinical genome-wide sequencing. This study aims to evaluate the feasibility and outcomes of integrating DECIDE into existing clinical frameworks with hopes of making it part of clinical care to increase the long-term sustainability of using this type of decision aid. The second affected sub-activity is assessing the process of integrating a genetic counselor into a primary care clinic (Cool Aid clinic) which is a multidisciplinary clinic mainly supporting populations with mental illness, addiction, and homelessness. To assess the process of integrating a genetic counselor into this multidisciplinary team, we conducted qualitative interviews with Cool Aid staff prior to the integration of the genetic counselor and 6 months after she was integrated.

2.4 | Pillar four: policy

This research pillar involves exploring possible pathways to the legal recognition of genetic counselors in Canada. The majority of this research is being conducted through literature reviews and surveys and interviews with clinical genetics providers. Due to the nature of this research, there has not been significant impact of the COVID-19 pandemic on progress.

3 | RESEARCH ACTIVITIES

In this section, we detail the impacts on research activities such as recruitment and methodology.

3.1 | Recruitment

The participants in the GenCOUNSEL project primarily include (a) patients and families who are considering or have undergone GWS and (b) genetics professionals who work in direct patient care and nondirect patient care settings. Patients and families were highly impacted by the pandemic, and we found lower levels of participation in research between March and September 2020 than we had expected based on our experience on previous research studies. The majority of the participants in our study are undergoing *clinical* GWS, and we have several research activities within Pillar 3 that are conducted alongside the clinical service, such as the use of DECIDE (electronic decision-aid designed for use in pre-test counseling; Adam et al., 2018; Birch et al., 2016). Because non-urgent clinical GWS in British Columbia was curtailed for over three months, this led to a near cessation of enrollment into this sub-study. From April to June 2020, we received 11 total referrals for the DECIDE research study, comparatively, from July to September 2020, we received 33 total referrals. The tripling of the referrals in this study is directly related to the gradual resumption of clinical GWS for non-urgent patients, however this is still only approximately half of our projected enrollment.

We were also concerned about recruitment into our research sub-activities that involved recruitment of genetics professionals because we wanted to be sensitive to personal and professional stressors related to the COVID-19 pandemic and did not want to overburden these individuals with requests to participate in research. To address this, for one of our Pillar one sub-activities involving a Delphi panel investigating genetic professionals' opinions about the future utilization of genetic services, we sent out a study invitation letter with a poll asking about current or future availability. We had 31/86 (36%) of invitees respond to our initial invite letter. The majority who responded (26/31, 84%) indicated that they were able to participate in the study at any time, which led us to launch the survey in June 2020 rather than delaying the launch of this study. Our institutions also mandated that research-based interviews with healthcare providers were not permitted between March-May 2020 unless they were being conducted for COVID-19 related-research purposes, which led to delays in recruitment for multiple sub-studies investigating the experiences and perspectives of healthcare providers.

3.2 | Methods

Although we had many disruptions, we have implemented some clear solutions when it comes to using alternative research methods in some project areas. We have several sub-activities that involve qualitative research and were designed to collect data through in-person stakeholder focus groups or individual participant interviews. Due to the COVID-19 pandemic, we are conducting these activities virtually instead, which has been shown to be as effective, and possibly cost-saving for researchers and participants (Rupert et al., 2017; Turney & Pocknee, 2005). For studies involving healthcare providers, using virtual research methods allowed us to increase geographic inclusivity and include participants in our focus groups who live across the country who otherwise would not have been included in an in-person event. We had originally planned for these focus groups to be limited to individuals who would be able to attend an in-person focus group in Vancouver, BC. We believe that in addition to increasing inclusivity, the virtual focus groups will also increase the generalizability of the findings from these focus groups to other areas of Canada. When indicated, we will take into account the provincial jurisdiction of the participant. This change in methods required an update to both our Research Ethics Board submission and a change in protocol to account for conducting virtual research. We recognize that for some participants, virtual research methods create barriers (e.g. people who lack reliable internet access or have low computer skills). One of the goals of the GenCOUNSEL project is to increase access to genetic services, especially for those who are underserved. To ensure that we are not creating unmanageable barriers to participate in research, we are planning to use a combination of virtual, in-person, and telephone methods to conduct qualitative research activities to increase inclusion. We have also been successful in implementing an electronic consent form through REDCap at

BC Children's Hospital Research Institute (Harris, 2009) for participation in two sub-studies involving patients and families. This has been successfully integrated in the evaluation of DECIDE (described above) and is being utilized in a sub-study understanding the experiences of certain cohorts undergoing GWS. We suspect that the implementation of these changes would not have occurred without the disruption to research caused by the COVID-19 pandemic.

4 | RESOURCE DIVERSIONS

We have experienced changes in resource utilization and allocation. In this section, we explain how changes in human resources, healthcare system resources, and Research Ethics Board resources led to changes, delays, or disruptions in our research.

4.1 | Human resource diversion

One of the most impactful and challenging issues to quantify has been the effect of human resource diversion on research productivity. This was encountered explicitly when team members' capacities were underutilized because they were unable to conduct their duties. For example, we had a dedicated full-time research assistant who was involved in enrolling and consenting participants in our DECIDE trial who were undergoing clinical GWS. Because nonurgent clinical GWS had been suspended, the majority of the tasks within this individual's job responsibilities could not be performed. Institutional policies related to COVID-19 did not allow for a reduction in the level of employment for such individuals (i.e. working part-time instead of full-time), in spite of this individual being unable to conduct research tasks. We also experienced a significant drop-off in productivity immediately upon transitioning to remote-work arrangements due to the lack of immediate access to data and software required to conduct job duties. Because of the initial immense demand on our information technology departments, we experienced understandable delays in resolving these issues in some cases.

Human resource diversion was also something our team encountered more implicitly in cases where project leads experienced a large administrative burden related to research curtailment and resumption, and transitioning to remote work arrangements, as well as the necessary time required to support team members' well-being during the transition. These activities were necessary and urgent, but it is worth noting that they had a substantial impact on research productivity. Our solutions for overcoming this strain have included a combination of strong and open communication about capacity and timelines, blocking specific days or times to be available for research versus administrative tasks, and fostering a culture of patience, understanding and support. We have also implemented recurring team meetings at a more regular cadence than when we were working in person. These meetings include a combination of structured and unstructured time to allow for the creation and maintenance of personal relationships between co-workers in addition to

discussing work related tasks. We have found that in the past many innovative solutions and ideas have come from casual interactions between team members, and, by having regularly scheduled but unstructured time to meet, we hope to create a virtual environment that fosters creativity and innovation.

4.2 | Healthcare system resource diversion

The absence of non-urgent clinical encounters involving genomic testing had a profound impact on enrollment into the DECIDE sub-study. In this study, participants who meet high knowledge and low decisional conflict thresholds are able to proceed with genetic testing without meeting with a genetic counselor. Of the small number of participants enrolled, approximately 10% of participants are choosing to meet with a genetic counselor after completing the decision aid, even after meeting the thresholds for knowledge and decisional conflict. Because this study launched immediately prior to transitioning to remote work, we are unable to compare that rate to pre-pandemic uptake. We will track these behaviors over time to determine if they change as the state of the COVID-19 pandemic changes.

We have two sub-activities investigating the impacts of integrating a genetic counselor within provincial laboratories or agencies in British Columbia and Quebec to measure the impacts of including a genetic counselor involved in funding decisions, test selection and utilization, and patient identification. As the beginning of the pandemic resulted in all provincial laboratory resources immediately being diverted to setting up COVID-19 testing protocols and urgent medical tests only, this led to complete suspension of the integration and research.

Another sub-activity (under Pillar 3) that involves qualitative research alongside a clinical service is the pilot study investigating the process of integrating a genetic counselor into a multidisciplinary primary care practice team (Cool Aid clinic) that supports vulnerable populations including those with mental illness, addiction, and homelessness. The genetic counselor in this setting started in January 2020 and began seeing patients independently after shadowing other care providers for two weeks. Within the Cool Aid clinic, the proposed model for integrating the genetic counselor into the team involved other members of the care team referring their patients for genetic counseling. For the genetic counselor, after a strong start in January, there was a sharp drop off in referrals with the onset of the pandemic, with only a single referral for genetic counseling made in March 2020. The Cool Aid clinic adopted a remote work approach late March 2020, and the genetic counselor was advised to put her efforts to facilitate new patient referrals on hold for nearly one month until mid-April 2020. The referral volume increased gradually since then, and, although at the one-year post-integration mark, this genetic counselor was still working remotely (briefly returned to clinic in person, part time for 7 weeks, June-July 2020), she was receiving approximately 15 referrals per month. Part of the original plan of having a genetic counselor in the same physical

space as other providers was that it would allow for same-day referrals when another provider was seeing a patient in person. Since in-person visits were disrupted, same-day referrals were not possible for large periods of time during the pandemic. The genetic counselor was the first member of the Cool Aid team to transition her patient care to remote service provision, by offering videoconferencing telemedicine appointments as an alternative to telephone, and this has been successful overall, with many patients endorsing the desire for face-to-face connection when they have access to the resources for videoconferencing, especially counselling given the importance of the therapeutic relationship. However, lack of necessary resources (phone, computer, internet, and a private space to engage in an appointment) have affected the uptake of appointments for the most vulnerable patients during this pandemic. The overall lower volume of referrals than expected this year, and the move to remote work for much of the Cool Aid team has introduced challenges with evaluating the process of integrating a genetic counselor into the team. Another part of this sub-study within the Cool Aid clinic involved a member of the research team (i.e. a genetic counselor who is not involved in the integration process) conducting interviews with other providers and staff within the Cool Aid clinic to understand their experiences with the integration of a genetic counselor into their team. We have had challenges recruiting Cool Aid providers for the qualitative interviews, given the demands of the pandemic on the providers' time and their limited interaction with the genetic counselor. Because of this, the interviews often tended towards a focus on the impact of the pandemic on overall clinic functioning and the integration of a new team member, rather than the process of integrating an individual with a genetic counselor skillset into the team.

4.3 | Research ethics board resource diversion

We also saw an impact on institutional Research Ethics Boards who were prioritizing amendments that were related to COVID-19 research. Although they were responsive to other requests for review, there were understandable delays related to Research Ethics Board processes. These delays were especially impactful for student research projects associated with GenCOUNSEL, where three projects were delayed in starting data collection. Further, the novelty of e-consent protocols required several amendments resulting in delays.

5 | TRAINING

A major component of GenCOUNSEL is capacity building through training graduate students, including thesis-based and directed studies projects for genetic counseling students (seven students in total). The students working with GenCOUNSEL experienced disruptions to their course work, including variable success in the transition to online learning in March 2020. They experienced delays in their research projects including delays in recruitment due to

inability to access onsite records, delays in accessing data offsite, and delays obtaining data from clinical sources and all of their research tasks had a greater administrative burden than they would have in a pre-pandemic landscape, which led to less independence. On a positive note, the transition to remote learning led to more opportunities for them to attend extra-curricular educational events and more flexibility with their schedules. As many conferences were virtual this year, this led to greater accessibility for students to attend due to the decreased cost and need for travel. Many of our students encountered personal challenges related to the pandemic such as having to relocate, concerns about employment, health-related stress, and family stress that affected their motivation towards conducting research.

In spite of receiving funding, we had to decline to participate in an institutional Work-Learn program for two semesters (Summer 2020 and Fall 2020) due to concerns with conducting in-person research. The Work-Learn program subsidizes meaningful employment opportunities for undergraduate students. A portion of the students' salary is provided by the Work-Learn program and a portion is provided by the research project (GenCOUNSEL). In the two previous semesters, (Fall 2019 and Winter 2020) GenCOUNSEL supported two Work-Learn students, but due to the uncertainty about conducting research and the difficulty with providing adequate supervision in remote work environments, we declined this opportunity. This was a difficult decision from a human resources perspective since over half of the salary is funded by the Work-Learn program. This resulted in 600 hr of subsidized human resources that we were unable to access due to remote work circumstances. Also, the majority of those interested in a Work-Learn placement with GenCOUNSEL in the past have been prospective genetic counseling students, and, given that this project is uniquely positioned to provide first-hand experience in genetic counseling research, it is mutually detrimental to be unable to offer these positions to prospective genetic counseling students.

6 | FUNDING

Some funding agencies have provided no-cost extensions to enable us to make up for lost productivity during the COVID-19 pandemic. However, this arrangement has not provided us with additional funding, which means that based on our current budget we will likely not be able to extend beyond our initial end date because salaries are the largest expense of our research. We have applied to receive funding from the Canada Research Continuity Emergency Fund, to subsidize future salaries. The criteria for this emergency funding were very stringent, and we will only receive a small portion of our total team salaries from this program.

Another unanticipated impact has been our ability to secure additional research funding. We have added a number of tasks to our sub-activities that we not in our original grant proposal to enhance our research project. Because these were not part of the original project plan, there is the need for additional research funds to

support these added tasks. Previously we had been successful in leveraging additional funding for our sub-activities through small grant competitions; however the current landscape for funding opportunities has changed, and there is more of a focus on COVID-19 related research. In our experience, there have been fewer opportunities to apply for additional funding since the COVID-19 pandemic began in March 2020.

7 | TAKE-HOME MESSAGES

7.1 | Be flexible, thoughtful, and creative

One of the biggest lessons reinforced this year is that our approaches to research need to be flexible, thoughtful, and creative to be able to adapt to unforeseen challenges. We have modified our research and recruitment methods and the settings in which we are conducting research to adapt to our changing circumstances. Through our changes in methodology, we have always maintained the goal of conducting high-quality and rigorous research, which at times has meant adapting our recruitment targets or timelines. Thoughtfulness and creativity in finding solutions to obstacles we have faced has allowed us to continue conducting research in ways that were respectful to the patients, families, and providers who participate in our research—the COVID-19 pandemic created conditions that forced us to think outside the box.

7.2 | Identify mechanisms for top up funding and no-cost extensions

We have learned the importance of highlighting 'lack of progress' of research to granting agencies and research oversight committees in order to obtain additional funding. Although highlighting deficiencies are counterintuitive to investigators, this transparency is essential. Additional and unanticipated funding application submissions are time intensive, however, they are also essential as we are committed to fulfilling research expectations to the best of our capacity.

7.3 | Maintain relationships: check-ins with students, co-investigators, and collaborators

The success of translational research is heavily dependent on relationships and cooperation between participants, clinicians, scientists, institutions, and researchers. The COVID-19 pandemic has been unique such that it has created challenges for the entire system, which is truly unprecedented. When the system experiences stress, this can lead to these relationships experiencing stress. The impact on mental health of the pandemic cannot be overstated. The importance of 'checking in' due to the isolation experienced by working remotely is by no means exclusive

to GenCOUNSEL. Having more regular laboratory meetings and mental health check-in meetings have helped to make this less difficult. Research trainees, with tight timelines and funding may require additional support. Ensuring all staff and trainees are aware of support resources (institutional, regional, etc.) is critical. In spite of the cessation of certain activities, continuing to 'check in' with collaborators has proven to be helpful with respect to ensuring they are coping well and sharing insights with respect to revised timelines and expectations.

As noted above, we have found lower engagement in our research studies than expected, from both patient and provider participants, and we speculate that this was due to the impacts of the pandemic on individuals' time, energy, and emotional capacity. We

are hopeful that the strength of our pre-pandemic relationships will support the rebound of our research productivity.

7.4 | Explore opportunities where virtual research can be beneficial

We have introduced more virtual research methods into our study, specifically in some of our qualitative research studies which has allowed us to expand our eligibility criteria and include individuals who are not geographically based near our research sites in Vancouver, British Columbia. Virtual methods allow us to broaden our inclusion criteria beyond geography and may lead to the

TABLE 1 Summary of challenges encountered because of the COVID-19 pandemic

| Area impacted | Specific challenges encountered | How this was addressed |
|---------------------|---|--|
| Research activities | <i>Recruitment:</i> Pre-emptive concerns in participation in survey-based study | Sent out initial invite letter asking if providers were available to participate in research, planned to delay study if responses were unfavorable |
| | <i>Methods:</i> Unable to hold in-person focus groups | Transitioned from in-person to virtual focus groups |
| | Challenges with obtaining signed consent forms | Developed an electronic consenting process |
| Resource diversion | <i>Human Resources:</i> Initial curtailment of on-site research | Prioritized work that could be done remotely, created safety plans for those who needed to be on-site |
| | Team members tasked with activities related to the COVID-19 response resulting in less time available for research-related tasks | Utilized productivity management tactics, scheduled more recurring team meetings, scheduled virtual social events to foster connection |
| | <i>Healthcare System Resources:</i> Pause in nonurgent genetic testing led to paused enrollment in sub-study | Waited until clinical sequencing resumed, prioritized other parts of the study while this was paused |
| | Remote work environment led to challenges in evaluating the implementation pilot study of a GC into a primary care setting | Used telehealth models to see patients remotely when possible, delayed research interviews with clinical team |
| | Diversion of laboratory resources led to inability to launch sub-study embedding a GC into a laboratory to assess test utilization and patient identification | This project is still paused while the provincial laboratories remain focused on the COVID-19 response |
| | <i>Research Ethics Board Resources:</i> Encountered delays with amendments | Waited for institutional research ethics boards to have capacity to review amendments that were not directly related to COVID-19 research. |
| Training | Rapid transition to remote learning and working led to delays | Prioritized other work that could be done remotely, created safety plans for those who needed to be on-site to conduct research |
| | Declined participation in institutional work-learn program | Opted not to participate due to inability to onboard and supervise remotely, planning to re-join this program |
| Funding | Initial grant awarded was due to expire in 2022, despite delays in research caused by the COVID-19 pandemic | Applied for and were granted no-cost extensions from some funding agencies, planning to apply for bridge funding when opportunities are available |

inclusion of unheard or underrepresented voices. Virtual methods can also lead to barriers for individuals who do not have access to necessary resources (Rupert, 2017). We are planning to use a combination of methods to increase the inclusivity and access to our research project, such as offering telephone and in-person options when appropriate, and continue to access to an interpreter for non-English speaking participants. Although many virtual methods were available prior to the COVID-19 pandemic, the shifted emphasis has encouraged us to prioritize these methodologies. Table 1 summarizes the challenges and ways in which the research group mitigated these issues.

7.5 | Fostering resiliency is integral to research

Given the varied backgrounds, and the previous clinical and research experience of the GenCOUNSEL team, to some extent, we have encountered every single one of the above listed challenges. What makes the COVID-19 pandemic so unique is that it has created an environment where we are all encountering these challenges at the same time. Of all the definitions of resiliency available, the one most applicable to conducting research during a global pandemic is that resiliency is 'the capacity of a dynamic system to adapt successfully' (Southwick et al., 2014). There have been previous studies highlighting the need to foster resiliency in genetic counseling and we believe that extends into genetic and genomic counseling research in addition to clinical practice (Wells et al., 2016). Resiliency is integral to research because even outside of the context of a global pandemic, research is a nonlinear process full of unforeseen challenges and it is our resiliency that allows us to adapt and find solutions.

8 | CONCLUSION

We have described the challenges that the GenCOUNSEL research project has faced in the past year due to unforeseen circumstances caused by the COVID-19 pandemic. As a large-scale project that is conducting multi-method research across a variety of settings, we have seen every aspect of our work impacted in some way and we anticipate that our study will continue to be affected in ways that we have not yet identified. Despite the challenges facing the GenCOUNSEL research project and genetic counseling field as a whole, we are optimistic that through adaptation and resiliency and we will find ways to move forward.

AUTHOR CONTRIBUTIONS

All authors made substantial contributions to the conception and design of the work. They were all involved in drafting the manuscript and/or critically contributing to the intellectual content. All authors reviewed the final version of the manuscript, and they agree to be accountable to all aspects of the work including the accuracy and integrity of the manuscript.

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COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

HUMAN STUDIES AND INFORMED CONSENT

The GenCOUNSEL research study was approved by and conducted according to the ethical standards of the University of British Columbia and McGill University Research Ethics Boards. All applicable international, national, and/or institutional guidelines were followed. For the sub-studies that involved research participants, informed consent was obtained for individuals who voluntarily participated in these studies.

ANIMAL STUDIES

No non-human animal studies were carried out by the authors for this article.

DATA SHARING AND DATA ACCESSIBILITY

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study, all data generated for this commentary are present in the publication.

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