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ARTICLE

ACMG Medical Directors' Special Interest Group survey: Current challenges for medical genetics clinics

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ABSTRACT

Purpose: The American College of Medical Genetics and Genomics Medical Directors' Special Interest Group (SIG) began in 2021 as a forum for directors of medical genetics clinical groups to share questions, concerns, current practices, and solutions regarding clinical operations. We report on the first 4 years of the SIG—its membership growth and SIG activities. We also present quantitative and qualitative results of a nationwide survey of 66 SIG members addressing recurrent questions from members regarding: wait times, volume of referrals, clinical workload expectations, and independent practice of genetic counselors (GCs) and advanced practice providers.

Methods: Cross-sectional survey of American College of Medical Genetics and Genomics Medical Directors' Special Interest Group members.

Results: We found that clinical full-time equivalents expectations are higher for medical geneticists than advanced practice providers, which were higher than for GCs. In 76% (44/58) of programs, GCs see patients independently, although many require a medical geneticist cosignature for orders, and only 51% (30/59) of programs report that GCs can bill independently. Clinic wait times for routine visits vary by subspecialty; the longest wait times are for general pediatric and adult genetic services (49% [21/43] of visits had wait times > 6 months), whereas wait times > 6 months were reported for only 26% (9/34) of cancer genetic visits, 7% (3/43) of biochemical genetics visits, and 0% (0/26) of prenatal visits. Urgent visit wait times were generally less than 2 weeks.

Conclusion: Wait times for clinical genetics appointments continue to increase compared with surveys from previous years. Medical genetics clinics are comprised of a heterogeneous workforce, and strategies to reduce wait times are similarly diverse.

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Introduction

The genesis of the Medical Directors' Special Interest Group (SIG) was one ACMG member asking another member a question about routine clinical operations. From that initial conversation we recognized that the ACMG had no existing forum to address the needs of clinical medical directors, which prompted a core group of volunteer leaders to create the Medical Directors' SIG in the Fall of 2021 with 19 original members. From the beginning, the goals of the group were to provide a venue to ask questions to other medical directors of genetics clinics, and share best practices and information among the group members. SIG membership is open at no charge to current ACMG members. The growth of the SIG has been entirely through word-of-mouth, and has grown to 83 members in 4 years. We developed a membership directory. After providing contact and basic information on clinic services provided and number and roles of clinical personnel, members receive access to a shared drive of published articles, data, and draft proposals contributed by SIG members. Our SIG activities have included: a listserv to query the SIG members, a shared drive of resources, virtual webinars and yearly hybrid virtual/in-person meetings held during the ACMG Annual Meeting, formation of workgroups, and a scientific session at the 2025 ACMG Annual Meeting.

Prominent topics of discussion in our Special Interest Group (SIG) have been finding solutions to lengthy clinic visit wait times and staffing and institutional productivity expectations. We recognize that productivity benchmarks for primary care or specific medical and pediatric specialties are not appropriate for the heterogeneity and complexity of medical genetics practice. To address this, we created a survey of current SIG members regarding information on their clinical practices and presented initial results of the survey at the 2025 ACMG Annual Meeting. This is the first publication arising from any ACMG SIG.

Three prior surveys of the genetics workforce capacity conducted from 2003 to 2019 reported an increase in clinic wait times greater than 3 months from 11% in 2003 to 30% in 2015 to 39% in 2019.[1-3] Over the same period, across all disciplines, geneticists reported the average number of new and return weekly visits increased from 10 patient visits in 2003 to 18 weekly visits in 2015, to 22.3 weekly visits in 2019. A 2023 survey evaluated the medical genetics workforce but did not include workload or wait times.[4] The purpose of our study was to evaluate the current state of workload expectations, wait times, and potential solutions.

Materials and Methods

SIG formation and membership

The ACMG Medical Directors' SIG was formed in the Fall of 2021. ACMG members joined by contacting one of the Co-Chairs (N.H.R. or F.M.H.) by email or in person. The process of joining the SIG as a limited member required confirming current ACMG membership, and adding name, institution and email to the SIG membership roster and listserv. Each limited member was then sent an email invitation to create a basic online profile of their clinic, including staffing, and the types of genetics services provided. After completing the clinic profile, they were considered full, participating SIG members and given access to a shared drive of resources and invited to additional SIG activities such as webinars and meetings. There are currently a total of 83 limited and full members, all of whom expressed interest in joining the SIG and provided an email address. They represent 64 institutions across 30 states, the District of Columbia, and 1 member in Canada.

Survey methods

We designed a survey on Google Forms with the intent of establishing a "state of the field" for academic genetic clinical practice, staffing, practitioner independence, and appointment wait times. The survey questions were derived from a previous survey addressing access developed by a workgroup consisting of members of the SIG. The current survey expanded upon questions from the initial survey to gather more granular data. The survey questions were reviewed by SIG leadership (N.H.R. and F.M.H.) before distribution. Survey questions are provided as a Supplemental Questionnaire. This study was determined to be exempt from review by the University of Michigan Institutional Review Board. The survey was circulated to SIG members via email and responses accepted over a roughly 1-year time period (from September 2024 through September 2025). Multiple reminders were sent to participating SIG members. Our response rate was 66/83 (80%). After the survey was closed, responses were compiled and screened for completion. The survey responses were manually reviewed. Some sites provided more than 1 survey response. For those sites, following manual review the data were kept as separate responses when the clinical services were clearly distinct, eg, separate pediatric and adult clinics at different hospitals under a single institution, such as a unified health system or medical school. The data were merged into 1 response for some sites. If necessary, the authors reached out to individual respondents for clarification. The total number of responses for each question varied based on the specific clinics under the supervision of the medical director at each site. Data were analyzed, descriptive statistics generated, and figures prepared using GraphPad Prism.

Results

Clinic structure and staffing

Medical directors of genetics clinics from 59 different institutions completed the survey (Supplemental Figure 1).

Genetics services were housed within several different departments, including Pediatrics, Obstetrics and Gynecology, and independent Genetics departments (Figure 1A). Of these, a majority offered multiple types of genetics clinics (Figure 1B). Other subspecialty clinics were prevalent, and those with a focus on neurologic, cardiovascular, and skeletal disorders were the most common.

Genetic counselors (GCs) provide the majority of clinical work hours as measured by clinical full-time equivalents (FTE), and advanced practice practitioners (APP) are less commonly utilized (Figure 1C). Genetic counselors are supported by a genetic counseling assistant at an average ratio of 5 GC FTEs to 1 genetic counseling assistant FTE. Clinical geneticist (medical geneticist [MD]) providers were expected to have more clinical sessions per week than GC or APP providers, spending a median of 6 half days in clinic compared with 4 half days for GCs and APPs for a fully clinical position (Figure 1D). For 60-minute visits, this corresponds to an expectation of 24 patient visits per week for an MD and 16 patient visits per week for GCs and APPs. At most institutions, GCs are seeing at least some patient visits independently from an MD (76% of respondents) and can sign orders with an MD cosignature (75% of respondents). In total, 51% of respondents note that their GCs can bill insurance independently, which implies that some institutions are offering GC only visits that are not reimbursed through insurance. Results varied widely across institutions, but a median of 20% of GC visits were conducted without an MD provider (Figure 1E). APPs are practicing largely independently, 90% of APP visits occur without an MD present. GC responsibilities varied, but most can order genetic testing, review patient charts, and call back results (Table 1).

Clinical load and appointment wait time

About half of respondents note an incoming clinical volume of greater than 50 referrals per week, with some institutions receiving as many as 300 (Figure 2). Wait times for appointments are highly variable between institutions, clinic types, and staffing models. Our survey identified a longer wait at most institutions than has been observed in previous studies. Pediatric, adult, and combined general genetic clinics had the longest waits, with about half of survey respondents indicating a wait time > 6 months (Table 2). Prenatal and biochemical genetic clinics had shorter appointment wait times, as might be expected given their higher acuity and urgency of concerns. Most institutions had urgent visit slots at what appear to be appropriate intervals, with nearly all biochemical genetics urgent visits scheduled within 2 weeks (Supplemental Figure 2).

With increased clinical volume one may expect to see a need for increased staffing, as well as longer wait times for an appointment. There does appear to be a trend toward higher staffing as measured by institutional FTE (Figure 3A). However, there was no obvious trend between total staffing numbers and appointment wait times (Figure 3B). There was also no obvious correlation between wait time and no-show rates (Supplemental Figure 3A). Institutions with longer wait times did tend to report higher expectations for the number of clinical sessions expected from MDs (Supplemental Figure 3B). This could be indicative of an institutional response to long wait times by having physicians hold more clinical sessions; however, it could also be interpreted to mean that higher clinical productivity expectations do not necessarily result in shorter wait times for appointments. Clinics with higher referral volume generally had longer wait times for appointments (Supplemental Figure 2). Looking at broad trends across institutions, there was no clear correlation between staffing of GCs or APPs and expected wait times; however, large institutions with lower reported wait times did tend to report higher FTE for MD providers (Supplemental Figure 4). One possible interpretation of this observation is that a higher level of MD staffing can lead to lower appointment wait times, although our survey was not designed to answer this question. The survey questions are provided as Supplemental Questionnaire.

Strategies for improving access

Our survey included a free text response section to identify any effective strategies that medical directors have used to improve access to their clinics. Most respondents use common-sense strategies, such as the use of patient reminders and a streamlined scheduling process. Several institutions have implemented policies in which they will not schedule patients with common referral indications that have a very low incidence of bona fide genetic disease and in which there are no formal recommendations for genetic testing, such as hypermobile Ehlers-Danlos syndrome or *MTHFR* variant testing. Many responses emphasize the efficacy of GC only clinics. However, the use of GC only clinics is limited by their ability to independently bill insurance and by the eventual need for most patients to be seen by an MD. One institution in which GC independent billing is not supported noted an alternative strategy: they have negotiated a contract with referring departments as a retainer to cover the cost of GC only visits for their most common referral indications. For example, a contract with their Pulmonology providers allowed for expedited evaluation of pulmonary fibrosis cases in GC only visits.

Discussion

The rise of genomic and precision medicine has led to increasing referrals and demand for clinical genetic

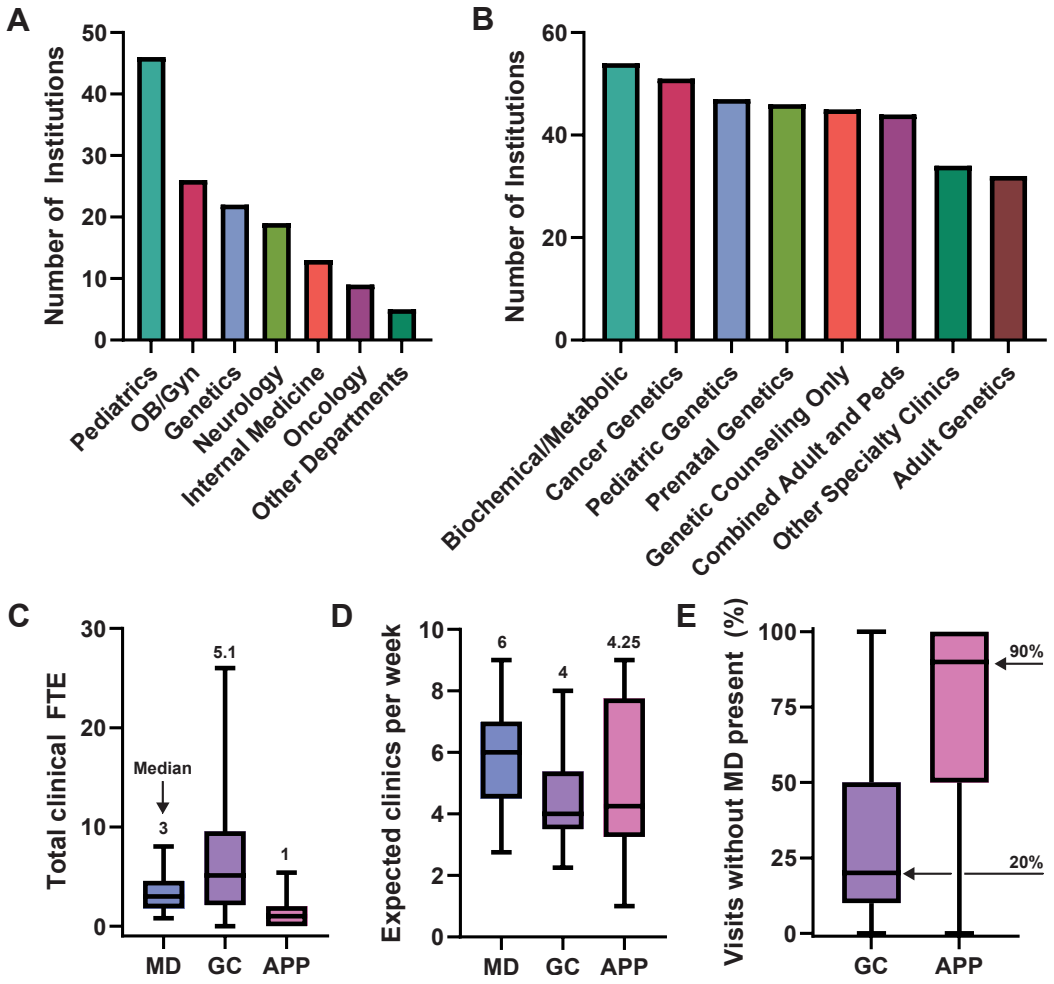

Figure 1 **Clinic structure and staffing metrics.** A. Respondents selected which departments house their genetics services, with some institutions selecting multiple departments depending on the services they provide. These results are plotted based on the number of responses for each type of overseeing department. B. Plotted are the types of clinics available at each institution by the number of responses. C. All respondents that provided information regarding the amount of clinical FTE for medical geneticist (MD), genetic counselor (GC) and advanced practice practitioner (APP) staff were plotted and the results displayed with median, interquartile range, and minimum/maximum values in a box plot. The median for each set is presented within each plot. D. All respondents that provided information regarding the expected number of clinical sessions (expressed as half-day clinics per week) for the equivalent of a 1.0 FTE clinical position were plotted and displayed as above. E. Plotted are the percent of clinic visits that were conducted without a medical geneticist for each provider type with the median percentage highlighted with arrows. FTE, full-time equivalent.

services.[1-3,5] The increase from 10 patient visits per week in 2003 to 18 patient visits per week in 2015 represents an 80% workload increase and the increase to 22.3 patient visits per week in 2019 represents a further 24% increase in physician geneticist workload. The current study found that a full-time clinical geneticist is expected to have an average of 6 half-day clinics scheduled per week. For a 60-minute patient visit, this corresponds to a clinical workload of 24 patients. Our survey did not ask about new versus return patient visits (in many practices, a return visit is shorter), so 24 patients is likely an underestimate for a 1.0 clinical full-time equivalent position.

Table 1 Summary of GC responsibilities

Genetic Counselor Responsibilities ($n = 61$)	(%)
Follow-up of test results	93
Ordering genetic testing	84
Precharting	84
Separate clinic notes are required for both GC and MD; GC does not complete MD note	56
Placing referrals	30
Ordering nongenetic testing or imaging studies	25
Clinic note for MD (MD is not required to write their own note)	20

GC, genetic counselor; *MD*, medical doctor.

The factors that enabled the increase in patients seen were not evaluated in prior surveys. We report qualitative responses to our survey regarding effective strategies for improving access. Respondents identified patient visit reminders, triaging referrals by implementing policies for common but low-yield indications, and genetic counseling only clinics as effective ways to use the limited resource of

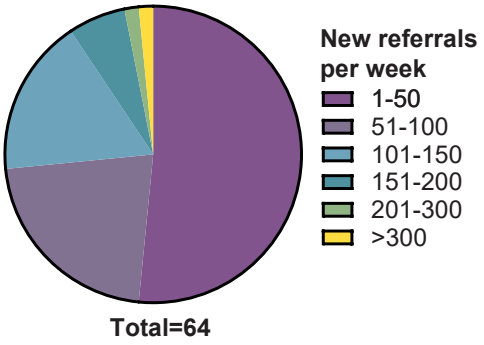

Figure 2 Clinical load as expressed by the number of new referrals per week. Survey respondents were asked to select a number of referrals per week that described their typical clinical volume; these were predetermined ranges as presented in the above figure.

clinician availability more effectively. The National Society of Genetic Counselors Professional Status Survey found that a wait time of >6 months for a new patient visit was seen for 5% of GC only visits but for 19% of physician plus GC visits.[6] Genetic counselor training programs have expanded significantly in the past decade to meet the growing need, but challenges remain regarding institutional or state licensing requirements for physician documentation or cosignature of GC visits.

We found that workload expectations averaged to 4 clinics per week for a GC, and 4.25 clinics per week for an advanced practice provider. These results are similar to those of a 2023 survey of APPs in the genetics workforce, which reported an average of 15 patients seen per week (SD 7.7).[7] This study also reported that APPs practicing genetics comprise only 0.02% of APPs, suggesting an area for potential growth. At least 1 academic center has effectively reduced wait times with a careful plan and investment in introducing APPs to the multidisciplinary genetics team.[8]

Previous surveys reported a trend of increasing wait times for genetics clinic visits, with 39% of visits with a wait time greater than 3 months in 2019.[3] Our survey results show wait times continue to increase, but with subspecialty differences. For example, 45% of pediatric and 46% of adult general genetics visits have wait times exceeding 6 months. In contrast, 26% of cancer genetics visits, 7% of biochemical genetics visits and no prenatal visits have a wait time of greater than 6 months.

The ACMG Medical Directors' SIG was launched in 2021 as a forum to serve the needs of ACMG members who are clinic medical directors. The rapid growth of the group supports the need and interest in our activities. Among the most pressing questions have been those regarding appropriate staffing, clinical FTE expectations, and wait times. This is the first nationwide survey addressing clinical genetics workload and wait times in the United States since 2019. This topic is clearly an area of interest to the members of the SIG, as demonstrated by our response rate of 80%, which represents a strength of our study. Follow-up surveys at regular intervals will allow for analysis of trends in the data over time, particularly given changes in staffing with shared or independent visits by GCs and APPs. Additional considerations regarding variations in the length and complexity of patient visits, new vs return visits, and trends in referrals for posttest counseling for genetic testing ordered by non-Genetics providers will also need to be included in future surveys. Future directions for our SIG are to consider and evaluate the effectiveness of newer strategies such as telemedicine, electronic consults, electronic health record tools, mainstreaming of clinical genetic testing, the use of artificial intelligence to support documentation to increase efficiency and improve provider well-being, all with the goal of increasing access to clinical genetics services, and reduce wait times.[9-12]

Data Availability

The authors will make available relevant survey data for the purposes of verifying or contextualizing the conclusions. Disclosure will be limited by the need to protect the privacy of the respondents. In addition, the authors will consider requests to supply relevant, unpublished data for the purpose of verifying or contextualizing the conclusions.

Table 2 Wait times for nonurgent new patient visits

Genetic Clinic Category	< 1 Month	1-6 Months	7-9 Months	10-12 Months	12-18 Months	>18 Months
Pediatric General ($n = 40$)	1 (2.5%)	21 (52.5%)	4 (10%)	4 (10%)	10 (25%)	-
Adult General ($n = 26$)	-	14 (54%)	6 (23%)	1 (4%)	5 (19%)	-
Combined General ($n = 43$)	1 (2%)	21 (49%)	9 (21%)	5 (12%)	7 (16%)	-
Cancer ($n = 34$)	5 (15%)	20 (59%)	3 (9%)	4 (12%)	1 (3%)	1 (3%)

	< 1 week	1-2 weeks	2-4 weeks	1-2 months	> 2 months	3-4 months	>6 months
Biochemical ($n = 43$)	4 (9%)	6 (14%)	12 (28%)	12 (28%)	-	6 (14%)	3 (7%)
Prenatal ($n = 26$)	2 (8%)	15 (57%)	7 (27%)	1 (4%)	1 (4%)	-	-

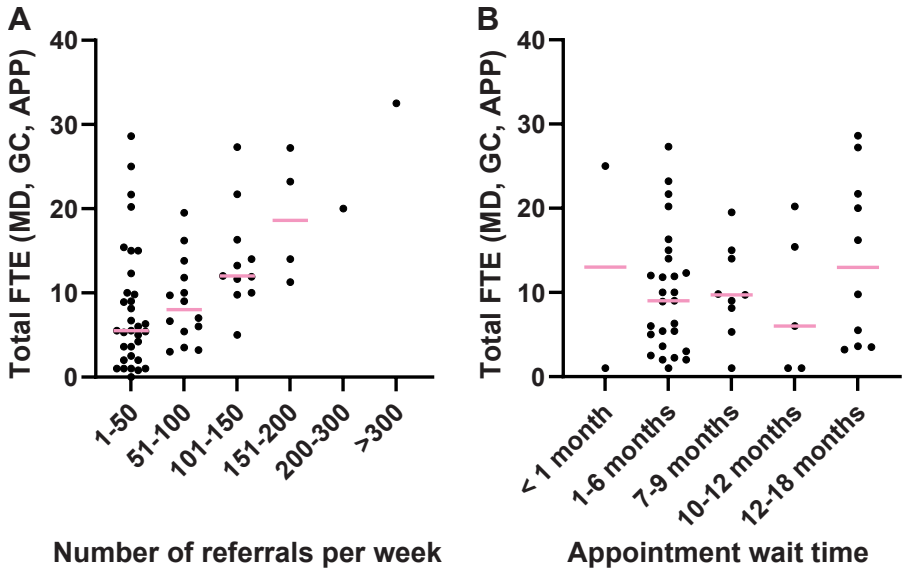

Figure 3 **Total clinical FTE correlates with institution size but not wait time.** A. The total amount of clinical FTE was pooled for all providers including medical geneticists (MD), genetic counselors (GC), and advanced practice practitioners (APP). Total clinical FTE was plotted against the number of referrals per week as well as B. The wait time for an appointment for a pediatric genetics clinic appointment, either in a standalone pediatric clinic or combined pediatric/adult general genetics clinic. Each response is represented by a single data point, and the median for each group is displayed as a pink bar on the graph. FTE, full-time equivalent.

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Author Contributions

Conceptualization and Methodology: F.M.H., C.E.K.; Data Collection: C.E.K., F.M.H.; Data Analysis: M.D., C.E.K., S.U.D., C.H.-E.; Writing-original draft: F.M.H., M.D.; Writing-review and editing: F.M.H., C.E.K., N.H.R., S.U.D., C.H.-E.

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Ethics Declaration

Ethics approval was obtained from the University of Michigan Institutional Review Board. This study was reviewed and deemed exempt as a quality improvement project.

Conflict of Interest

The authors declare no conflicts of interest.

Additional Information

The online version of this article (https://doi.org/10.1016/j.gimo.2026.104392) contains supplemental material, which is available to authorized users.

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