

Title: The composition and capacity of the clinical genetics workforce in high-income countries: A scoping review

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Abstract

As genetics becomes increasingly integrated into all areas of healthcare and the use of complex genetic tests continues to grow, the clinical genetics workforce will likely face greatly increased demand for its services. To inform strategic planning by healthcare systems to prepare to meet this future demand, we performed a scoping review of the genetics workforce in high-income countries, summarizing all available evidence on its composition and capacity published between 2010 and 2019. Five databases (MEDLINE, Embase, PAIS, CINAHL, and Web of Science) and grey literature sources were searched, resulting in 162 unique studies being included in the review. The evidence presented includes the composition and size of the workforce, the scope of practice for genetics and non-genetics specialists, the time required to perform genetics-related tasks, caseloads of genetics providers, and opportunities to increase efficiency and capacity. Our results indicate that there is currently a shortage of genetics providers and that there is a lack of consensus about the appropriate boundaries between the scopes of practice for genetics and non-genetics providers. Moreover, the results point to strategies that may be used to increase productivity and efficiency, including alternative service delivery models, streamlining processes, and the automation of tasks.

Key words: workforce, clinical genetics, genetic counselor, clinical geneticist, human resources

1. Introduction

The utilization of genetic testing in clinical settings has greatly increased over the past 10 years,¹ with one study projecting annual growth in genetic test use of 23% between 2014 and 2024.³ This trend has been driven in part by the rapid decline in the cost of sequencing⁴ and has been accompanied by the advent of clinical genome-wide sequencing (GWS; including exome and genome sequencing).⁵ As a result, demand for counseling and consultations with clinical genetics professionals has also grown rapidly, resulting in concerns about potential workforce shortages and insufficient health system capacity to meet this growing demand.^{6,7,8} Moreover, continued growth in the clinical implementation of GWS is likely to put further pressure on the clinical genetics workforce because GWS requires more intensive decisional support for both patients and healthcare practitioners than for less comprehensive genetic tests. This is due to the possibility of secondary findings, data storage and privacy concerns, difficulty in interpreting test results, and the need to support patients who must deal with the complex, and often unanticipated, psychological and informational impacts of genomic testing.⁹ Indeed, it is unclear how the genetics workforce will be able to meet the growing demand for GWS testing, given that the literature suggests that there is already a shortage of clinical geneticists (CGs; i.e., physicians with a board-certified specialization in medical genetics) and genetic counselors (GCs) – e.g., a substantial number of CG residency openings go unfilled each year,¹⁰ and it has been estimated that there are only 7000 GCs worldwide.¹¹

Understanding the current composition and capacity of the clinical genetics workforce is a prerequisite for effective strategic planning by healthcare systems in light of the expected growth in demand for genetics services over the next 10-20 years. As such, our objective for this scoping review is to summarize the available evidence on the current state of the genetics workforce, focusing in particular on the number and types of professionals involved, their ability to deliver genetics services, and opportunities for increased efficiency through task-sharing, delegation, alternative service delivery

models, and augmentation of services through the use of technology. Previous reviews have assessed present and future characteristics of the GC workforce,^{12,13} alternative service delivery models,¹⁴ genetics education content,¹⁵ and attitudes of healthcare providers about their perceived roles in genetics.¹⁶ However, these studies have tended to focus on a single indication or setting, which is suboptimal given the ability of clinical genetics professionals to practice in all clinical areas and the high level of international labour mobility for genetics professionals in regions like North America. As a result, our review aims to compile the available evidence about the composition and capacity of the clinical genetics workforce across all high-income countries and regions, with the goals of better understanding the global labour market for genetic healthcare professionals and of identifying possible policy solutions to labour shortages that could be applied in multiple jurisdictions.

2. Methods

This review was conducted according to the Arksey and O'Malley methodological framework for scoping reviews,¹⁷ along with recommendations from the Joanna Briggs Institute¹⁸ and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines.¹⁹ A full description of our methods appears in the *Supplemental Appendix*.

2.1 Search Strategy

We searched five databases (MEDLINE, Embase, CINAHL, PAIS, and Web of Science) for articles published between January 2010 and April 2019. Grey literature publications were identified from sources listed in the Canadian Agency for Drugs and Technologies in Health Grey Matters Checklist and from relevant professional organizations related to the genetics workforce.²⁰ In addition, new publications identified through a PubMed alert for related publications were included until the end of primary data extraction (July 30, 2019), and reference mining was used to identify additional studies.

2.2 Study Selection

Publications in English, French, or Spanish that described the genetics workforce in high-income countries (as listed in the *Supplemental Appendix*)²¹ were retained. Relevant characteristics included the number and type of genetics professionals, scope of practice, time needed for tasks, legal recognition, wait times, caseloads, referral patterns, professional issues, impacts of technology, and compensation structure. Non-empirical papers and professional practice and clinical evaluation guidelines were excluded. Title and abstract screening and full-text review were all performed by two independent reviewers (NK, KB), with any disagreements resolved by a third reviewer (ND). Potentially relevant studies identified through citation mining and during the course of searching for grey literature were evaluated for inclusion **based on the same criteria**. The reasons for exclusion of database search records are reported in the PRISMA diagram (**Fig 1**).

2.3 Data extraction

Data extraction took place in two phases. Primary data extraction was conducted by one of two coders and a common set of data points were extracted for all studies, including basic study characteristics, data sources and methods, healthcare professional data, and factors influencing workforce supply and demand. The results were grouped according to three main themes: 1) number and type of individuals in the workforce, 2) scope of practice, and 3) interventions that increase capacity. The results were synthesized within their groups, and secondary data extraction was conducted as necessary on subsets of studies to extract data on specific themes of interest identified during the course of analyzing the results of the primary data extraction.

3. Results

Full-text review was performed on 304 publications from the database search, of which 121 were included in the review (**Fig. 1**). Twenty-six grey literature documents, and 23 additional peer-reviewed studies found through citation mining and during grey literature search were also included

after full-text review. In total we included 170 records reporting on 162 unique studies (*Supplementary Table A*) The majority of included studies focused on the North American (101/162, 62%) or European (32/162, 20%) workforces (**Table 1**). In addition, sixty-nine percent (111/162) reported on genetics providers and 48% (78/162) discussed non-genetics providers.

For the purposes of presenting thematic results in this review, we created a conceptual model of the genetics workforce outlined in **Fig. 2**, which divides the workforce into genetics specialists and other healthcare providers and defines capacity as the collective ability of these two groups to perform the tasks involved in delivering clinical genetics services. The key drivers of capacity that emerged from our results were: 1) the type and number of genetics specialists; 2) their scopes of practice; 3) time spent on genetics tasks; 4) caseloads; 5) the scope of practice for non-genetics specialists who provide genetics services; and, 6) opportunities to increase genetics services capacity.

3.1 Type and number of genetics specialists

The number of full-time equivalent (FTE) providers per 100,000 inhabitants is a commonly used metric in healthcare planning. Although there was no agreement in the literature about what the ideal ratios would be to provide adequate genetics services, the number of GCs available to meet clinical demand in several jurisdictions (the United States, Europe, Chile, and Australia) was estimated as between 0.2 and 1.2 FTEs per 100,000 inhabitants,²²⁻²⁹ and five of these studies reported a shortage of GCs based on these ratios.^{22-25,29} Workforce surveys conducted between 2016 and 2019 indicated that there were approximately 4900 GCs in the United States and Canada, of which over 400 work in Canada.³⁰⁻³² The number of students enrolled in genetic counseling programs in North America has increased by 40% since 2012.^{33,34} As of 2017, there were 220 GCs working in clinical roles in Australia out of 677 individuals who hold an Australian genetic counseling degree.^{28,35} In 2012, it was estimated that there were 494 GCs and 122 genetic nurses in Europe.²⁷ The regulatory framework for GCs and genetic

nurses was highly variable across jurisdictions, and a number of publications discussed different elements of legal regulation, professional recognition, registration, and licensure.^{3,27,35-39}

Provider-population ratios for CGs were estimated as 0.3 FTE per 100,000 inhabitants in Chile and 0.6 FTE per 100,000 inhabitants in Australia, and it was argued that these ratios indicated a shortage.^{22,23,28} Included studies reported the absolute number of CGs in Portugal (30 practicing), Chile (28 practicing), the United States (over 250 practicing survey respondents), and Australia (approximately 150 medical genetics fellowship graduates).^{28,35,40} Approximately five new CGs graduate in Australia per year, and it was estimated that in the next 15 years, 25% of Australian CGs will retire.²⁸ Three publications about North American training programs reported that about half of medical genetics residency spots remain unfilled each year,^{10,41,42} and there were also vacancies in genetics pathologist residency programs.⁴³ In addition, up to half of employment positions for CGs were vacant in the United Kingdom and the United States.⁴⁴⁻⁴⁶

There were fewer publications of this type about the laboratory workforce. According to two surveys, there were approximately 300 “clinical laboratory geneticists” (CLG) in Europe. The CLG title is available in 60% of European countries and, although the educational pathway and scope of practice depends on the subspecialty and country, this position is usually filled by a non-medical doctor who holds a PhD in genetics and/or has other specialized training.^{47,48} Similar roles exist in the United States and Canada (with varying specializations and workforce challenges), but no studies reporting on the CLG workforce in North America were found. In 2017, there were 51 senior genetics pathologists in Australia.³⁵ Four publications described laboratory staff in Canada and the United States, finding that only a small proportion of individuals (1-5%) were recognizable as being specialized in genetics.⁴⁹⁻⁵² Two workforce surveys of genetic laboratory scientists in the UK National Health Service showed that the largest employee groups were clinical scientists and genetic technologists/practitioners (39.7% and 31.5% of workforce in 2016); and there was a small group of bioinformaticians employed (30 in

2016).^{53,54} Workforce data showed the total number of staff increased by 41% over the prior 6 years while the FTE equivalent increased by 39%.⁵⁴

3.2 Scope of practice for genetics healthcare providers

A number of studies attempted to delineate the perceived scope of practice of GCs and CGs. **Table 2** summarizes genetics related tasks. Overall, it was agreed that most tasks could be done by either type of provider. Taking family histories, risk assessment, patient education, and psychological assessment and support were considered appropriate for GCs by both GCs and CGs,^{16,40,55,56} whereas medical examination, management of complex cases, and making diagnoses were deemed to fall within the exclusive purview of CGs.^{16,26,55–58} Administrative tasks such as initial patient contact,^{26,37} appointment logistics, handling testing samples, and billing were frequently performed by GCs.^{35,56} Whether a GC took on tasks traditionally performed by an CG was correlated with years of experience and professional relationship with the CG,^{57,59} rather than more training or education.⁵⁷ In a European study, 74% of GCs ordered genetic tests at least sometimes,³⁷ and in an Australian study looking at genomics tasks, 26.2% of GCs and 85.7% of CGs ordered genome or exome sequencing.³⁵ In contrast, in some countries, the scope of practice for GCs faced strict legal constraints – for example, in Austria genetic counseling can only be delivered by a physician.⁶⁰ When nurses work as genetics nurses, the scope of practice appears to be analogous to GCs. Five studies discussed the roles of nurses as specialists providing genetic counseling, one of which also described the role of midwives.^{27,37,61–63}

Frequently cited clinical specialties for GCs in direct patient care were cancer, prenatal care, general genetics and pediatrics.^{25,35,64} As well, areas of specialization for GCs involved in direct patient care were reported in private practice settings,⁶⁵ pharmacogenomics,⁶⁶ and public health.⁶⁷ A growing number of GCs take on roles beyond the provision of direct patient care, with the proportion of GCs in the United States working in direct patient care having decreased from 65% in 2016 to 59% in 2019. The

most common employment classifications for GCs working in non-direct patient care were industry, education, research, and public health.^{24,31} While genetic counseling assistants (GCAs) or extenders have been integrated in some clinics as a way to provide more time for GCs to practice at the top of their scope, the boundaries of practice for GCAs are not well defined. GCs typically agreed that data entry, coordinating samples, and administrative tasks were appropriate tasks for GCAs, and while some felt that GCAs should be able to return negative test results to patients there was general agreement that it would be inappropriate for GCAs to return abnormal test results.⁶⁸⁻⁷⁰

Laboratory GCs have emerged as a subspecialty and the main roles include liaising with patients or ordering providers, administrative duties, interpreting test results, and reviewing laboratory reports.⁷¹⁻⁷³ Several studies described the involvement of GCs in test triage as part of laboratory utilization management.⁷⁴⁻⁷⁷ Also in the laboratory, CLGs can be the responsible head of a laboratory performing human genetics tests in 73% of the countries that recognize this title, according to a survey of more than 50 European and non-European countries.⁴⁸ Responsibilities of the CLG vary by region, and can include writing and signing laboratory reports, results interpretation, teaching, and (less commonly) counseling patients.⁴⁸

The studies above discuss the current scopes of practice for genetics providers; however, new testing technologies and applications, like GWS and direct-to-consumer testing, have the potential to impact the scopes of practice for these individuals. In a survey of Australian genetics specialists, GCs reported more pre-test responsibilities and CGs were more involved in test interpretation tasks when GWS was used compared to when other tests were used.³⁵ When surveyed about preferences for future roles, Australian GCs indicated a willingness to be involved in variant curation and classification, but follow-up interviews revealed this was with the goal of supporting patient care through better understanding of genomic test processes, rather than out of a desire to transition into laboratory GC roles.²⁸ In another study, GCs were unsure if variant interpretation fell within their scope of practice but

acknowledged that GWS would increase the complexity of their practices, although it would likely build on the core skill set that GCs already possess.⁵⁸ Direct-to-consumer testing also impacted the scope of practice of genetics providers but there was uncertainty about what role GCs and CGs ought to play in counseling, interpreting and confirming results or providing education for tests obtained in this way.^{78–80}

3.3 Time spent on tasks

A time study of GCs in Michigan found that GCs spend 20% of their time on face-to-face interactions with patients, 64% on other patient-related activities (including case preparation, follow-up including documentation, and administrative tasks), and 16% on other tasks such as research and teaching.⁶⁹ Notably, this study estimated that three hours of patient-related activities are performed for every 0.78 hours of face-to-face appointment time.⁶⁹ Similarly, other studies have found that the most time consuming GC activities are patient-related activities (e.g., letter writing and documentation),^{69,81–83} though GCs in general practices spent more time on these than GCs in specialty practices.⁸³

The time needed to provide pre-test counseling varied widely depending on clinical setting, from less than ten minutes in prenatal screening to typically close to one hour when exome sequencing was performed (*Supplementary Table B*).^{35,81,83–97} Typically, the median time for pre-test counseling was 30–60 minutes.^{35,81} Factors that were associated with longer pre-test counseling included joint appointments that included both a GC and a medical doctor, and pediatric testing.^{58,89,96} Shorter pre-test counseling was associated with online, group or telephone counseling, prenatal or cancer indications, and genetic counseling provided by non-genetics specialists.^{93,97} The time needed for post-test counseling appointments ranged from less than one minute for a negative prenatal screen⁹³ to one to two hours when exome sequencing was performed.^{35,64,82,84,86,88,89,91,93,96–98} Workforce surveys reported that most post-test appointments are between 30–60 minutes^{35,64} and, in general, estimates of times spent on post-test counseling tended to be less than for pre-test counseling, unless GWS was

performed.³⁵ Specifically, an Australian workforce survey reported that GWS took an additional 2.0 hours of GC time and 1.5 hours of CG time per patient as compared to for other tests, and CGs spent more time (~9.0 hours) than GCs (~8.5 hours) per GWS patient.^{28,35} Increased time spent on GWS patients is driven by the time needed to facilitate informed consent,⁵⁸ convey complex results to patients,³⁵ review medical records, prepare to discuss unfamiliar genetic results, and analyze and interpret test results.^{35,82,96,99}

3.4 Caseloads

The caseloads reported in this section refer to the typical number of patients seen per month by each provider type. Genetic counselors had varied caseloads that were highly influenced by specialty.^{35,69} The average monthly caseloads for GCs seeing patients varied by country and study and were self-reported by GCs in Canada (averages of 26³², 30³⁶, and 44¹⁰⁰), the United States (averages of 40⁶⁹ and 51.9⁹⁵, with the latter including other modes of delivery than face-to-face), and Australia (23³⁵). Of North American GCs who provided direct patient care, the highest monthly caseloads were for GCs working in genomic profiling/personal genomics (i.e. use of genomic information without a clinical indication), preconception counseling, and assisted reproduction, whereas the lowest monthly caseloads were in newborn screening and public health.^{64,95} The average monthly caseloads for CGs also varied by country and study and were self-reported by CGs in the United States (averages of 72⁴⁶ and 68⁸¹) and Australia (31³⁵). A study from the United States compared data from 2015 to historical data and found that the patient caseload for CGs had almost doubled, from 10 patients per week in 2005 to 18 patients per week in 2015.⁴⁶

3.5 Scope of Practice for Non-Genetics Healthcare Providers

Non-genetics healthcare providers (HCPs) are defined as providers who are not specifically trained as genetics providers but undertake genetics related tasks. Ten studies assessed non-genetic

HCP practices for family history taking and providing risk assessment for genetic disorders.^{63,87,101–108}

Primary care providers, gastroenterologists and oncologists reported that they wanted standardized tools for taking family histories¹⁰⁵ such as short family history questionnaires or electronic pedigree tools.^{102,106–108} However, when these tools were piloted, they did not appear to have a substantial impact on practice.^{106,107} A review article discussed genetics education interventions for primary care providers and found that education could lead to changes in knowledge and confidence but rarely translated to changes in practice.¹⁰⁹ Five studies assessed non-genetic HCP preparedness for managing genetic information and found that the main concerns arose from uncertainty regarding clinical utility, lack of time, no existing workflows, and concerns about managing psychological impacts of genetic information.

110–114

There were several studies about the practices of non-genetic HCPs in ordering genetic testing or referring their patients to a genetics specialist. Providers such as neurologists, psychiatrists, pulmonologists, dermatologists, and cardiologists were involved in ordering genetic testing, and the frequency and comfort level varied by setting.^{115–120} In studies that assessed referral patterns, between 9% and 58% of non-genetics HCPs reported that they had never referred a patient to a clinical genetics service for consultation.^{91,116,117,121} In these studies, neurologists and psychiatrists both had lower referral rates to genetics, but neurologists were more likely than psychiatrists to have ordered genetic testing.^{120,116,117} Overall, the main themes cited as barriers to referral were low perceived benefit for their patient, high costs, and limited availability of services.^{97,118,121–123} Two studies assessed the use of interventions to increase referral rates.^{124,125} One study demonstrated that the introduction of a Genetics Referral Toolkit designed specially to target barriers to referral (which included a referral template, genetic risk checklist, and a family history worksheet) improved referral rates in a cancer setting.¹²⁵ A second study introduced online educational modules to non-genetics HCPs, but although

providers believed that they had increased their referral rates these remained unchanged after the intervention.¹²⁴

The two main indications for which non-genetics HCPs provided genetic counseling were prenatal screening by obstetrician-gynecologists and hereditary cancer syndromes mainly by surgeons and oncologists.^{87,94,126–134} An assessment of the content of pre-test counseling for prenatal screening by obstetrician-gynecologists found that they met the American College of Obstetricians and Gynecologists recommendations for genetic counseling in only 1.1% of cases – notably, the disadvantages of screening were only discussed with 50% of patients.^{94,135} Several studies assessed the practices of non-genetics HCPs for genetic counseling for hereditary breast and ovarian cancer,^{87,126,131–134} with two studies finding that a significant portion of providers did not discuss the psychological impacts or the benefits and limitations of testing.^{87,126}

One area of clinical care in which genetic testing by non-genetics HCPs has expanded is hereditary cancer, either by mainstreaming of a test (offering genetic testing in an oncology clinic, where pre-test counseling and genetic test ordering would be done by an oncologist) or through rapid testing for individuals affected with cancer where results may impact treatment decisions. Most studies investigating attitudes found that the majority of providers believed that surgeons were the most appropriate providers of genetic testing.^{98,136,137} However, one survey of surgeons found that they did not believe it was their role to offer genetic testing and preferred to refer patients.¹³⁸ While most studies found that oncology providers were positive about mainstreaming, others were concerned that mainstreaming would increase workload beyond capacity.^{138,139} Five studies that described oncologists' ordering practices for genetic testing on tumor samples for treatment decision-making purposes found that oncologists tended to order more genetic tests^{140–144} than were recommended by professional guidelines.¹⁴⁵

There were several additional studies that compared genetics providers and non-genetics HCPs.^{82,93,97,110,146–152} They described differences in provider knowledge,¹⁴⁷ patient management,^{82,93,110,113,146,149,150,152} time and costs needed for tasks,^{82,93,97,150} and who was involved in providing care.^{60,82,93,97,146,151,152} Notably, one study identified and reported negative patient outcomes arising from non-genetics HCPs providing genetics services, such as psychological impacts on patients, insufficient counseling, inappropriate testing/screening, medical mismanagement, and poor healthcare resource stewardship.¹¹⁰

3.6 Opportunities to increase capacity

Clinical genetics services have traditionally operated using a two-visit model with in-person pre- and post-test counseling appointments. Increased demand for services has led to the adoption of alternative service delivery models and technological innovations to enhance access and capacity. These include deviating from the traditional two-appointment counseling model (e.g. pre-test only or post-test only),^{25,64,88,153} use of group genetic counseling,^{85,154} co-counseling by GCs and CGs,^{26,37,155} triage of patients for GC-only appointments,^{26,155} and using telehealth for counseling^{84,86,156–161} (*Supplementary Table C*). Genetics providers often operate using more than one service delivery model^{153,155} and adapt their approach in response to patient needs based on the complexity of the case^{26,37,155} and insurance requirements.¹⁵⁵

Although alternative service delivery models allowed GCs to see more patients, some providers were concerned about a reduction in the quality of service.⁸⁸ While group counseling was associated with shorter appointment times and was perceived as acceptable by patients, satisfaction was higher for individual counseling.^{85,154} Telehealth genetic counseling was found to increase access, reduce the cost of service, reduce wait times (at least in some studies), and be acceptable for patients (though less so

for providers).^{84,86,156–159} One study showed that offering genetic counseling through a virtual clinic allowed 2.7 telehealth genetic counselors to cover the same patient load as four in-person counselors.¹⁵⁹

As described previously, the two alternative service delivery models most used in specialty clinics were the mainstreaming of genetic testing and embedding a GC into interdisciplinary settings. Mainstreaming is common in oncology settings and has been shown to reduce wait times and decrease costs,^{98,137–139} while embedding a GC in an oncology or cardiology clinic increased the number of patients seen and decreased wait times and appointment length.^{92,162–164} Having a GC embedded in a cardiology clinic led to better identification and triage of patients for genetic counseling and also led to an increased referral rate for patients with syndromic features for a complete genetics consultation.¹⁶³

Additional studies reported on quality improvement, task-sharing between different provider types, or information technology innovations such as automation of processes and online administrative tools. Some studies streamlined workflow processes or implemented a technical or automated element and then measured impact on capacity by assessing the time saved or impact on patient throughput.^{165–171} For example, one group developed a workflow for insurance pre-authorizations, streamlining the process and reducing administrative tasks done by clinicians by delegating these tasks to non-clinicians.¹⁷⁰ Overall, these interventions saved or re-distributed time and were seen as satisfactory. Effective task-sharing through delegation of administrative or patient-related tasks to genetic counseling assistants or extenders was also reported as a way to enhance workflow by enabling GCs and CGs to focus on clinical tasks^{70,172} and see a higher volume of patients.⁶⁸ Quality improvement through utilization management was also reported as a way to increase appropriate use of genetic services. GCs have been shown to play an important role in utilization management through patient identification and triage^{156,173} and through reviewing genetic test requests in a laboratory setting,^{74–77} resulting in a reduction in inappropriate testing.^{75,77}

4. Discussion

This review describes the composition of the clinical genetics workforce in high-income countries and identifies a range of factors that influence its capacity, including the number and types of relevant professionals, the scopes of practice of genetics and non-genetics specialists, patient caseloads, time spent performing genetics tasks, and potential opportunities to increase efficiency. These factors are likely to be key drivers of the genetics workforce's ability to meet the growing demand for clinical genetics services in the coming years, and by summarizing relevant evidence this review aims to inform and facilitate strategic planning by healthcare systems to prepare for the expected future growth in the demand for genetics services.

A consistent theme in the literature is that the current capacity of the clinical genetics workforce is insufficient to meet existing demand for genetics services. Many of the reviewed studies pointed to an undersupply of genetics specialists, which can result in long wait times for routine referrals to CGs and GCs, ranging from a few months to over one year,^{46,139,156} and sometimes lead non-genetics professionals to be less likely to refer their patients to genetics clinics. However, these claims were not made in reference to a comprehensive evidence-based assessment of workforce needs, and there was limited data available on the CG and bioinformatics workforces and most high-income countries.²¹ Moreover, the types of outcomes reported were not standardized and tended to differ between the types of professions. The data on the CG workforce was limited to higher level surrogate outcomes as compared to the more detailed metrics describing the GC workforce, and studies on non-genetics HCPs focused primarily on the education and skills required to deliver services rather than on metrics like case loads, wait times, and task completion time.

Policies aimed at increasing the size of the genetics workforce are on their own unlikely to succeed in boosting system capacity enough to meet current, let alone future, demand. For example,

while the genetic counseling workforce has grown substantially in the last ten years, the number of non-clinical roles has also grown, so this has not directly translated into the same levels of growth in system capacity for direct patient care (e.g. only 59% of GCs in the United States working in direct patient care settings in 2019 as compared to 84% in 2012).^{24,31} As a result, many of the publications in this review focus on innovative ways of working as a way of improving efficiency, which can expand capacity while maintaining the size of the workforce constant.

One approach to increasing the efficiency of the clinical genetics workforce is to implement policies to facilitate the ability of professionals to practice at “top-of-license” (e.g., the use of GCAs to ease the administrative burden on GCs). However, for this to be an effective strategy, broad agreement on the scope of practice for relevant professionals is necessary. While our literature review revealed general agreement that much of the accepted current scope of practice for GCs and CGs overlaps (with the exception of medical tasks such as physical examinations of patients and making diagnoses, which are acts reserved for CGs), there was uncertainty about how scope of practice would be impacted by broader clinical implementation of GWS. In addition, the models used for legal recognition of GCs in different jurisdictions can have a significant influence on the types of tasks that can be delegated or performed independently by GCs. Several different models of legal recognition and regulation of GCs are described in the literature,^{3,27,35–37,39,55} and, although such recognition and regulation may enhance patient safety, the impact of different models on workforce capacity is unclear.

A second critical determinant of a healthcare system’s overall capacity to provide genetics services is the role of non-genetics HCPs. Their involvement in taking family histories and conducting risk assessments, genetic counseling, and testing can increase capacity, but the evidence suggests that this task-sharing may be challenging to implement due to inconsistencies in willingness and competence to perform these tasks.¹⁷⁴ This is illustrated by studies that evaluated the impacts of educational and technological interventions for primary care physicians and oncologists on increasing the identification

and referral of genetically at-risk patients, which were usually found to have limited impact on practice behaviors. Additionally, the literature suggests that there are possible harms that can arise from non-genetics providers performing genetic counseling and testing.^{110,175-177} It is therefore imperative that non-genetics HCPs who do take more prominent roles in the provision of genetic counseling and testing are well prepared to provide these services to ensure appropriate patient ascertainment, testing, and follow-up care.

Finally, our review identified a range of initiatives undertaken to increase capacity through the use of more efficient service delivery models (e.g. incorporating decision aids) and the augmentation of services. This approach is likely to become increasingly important in the future as the development and use of electronic decision aids and artificial intelligence (e.g. chatbots) in clinical genetics services moves forward.¹⁷⁸⁻¹⁸⁰ Many studies highlighted the potential of alternative service delivery models, and while a recent systematic review of randomized controlled trials of outcomes of genetic counselling found that these can be as effective as in-person counselling in some settings (e.g., women at risk for hereditary cancer),¹⁸¹ it is important to emphasize that there remains a subset of patients for whom appropriate genetic counseling and testing will require the traditional in-person two-appointment model. Care needs to be taken when implementing efficiency improvement initiatives to ensure that appropriate services are available for all patients.

Ultimately, the rapidly changing landscape of genetics service provision, driven in part by the growing use of more complex tests like GWS, is likely to place additional strain on the capacity of the clinical genetics workforce. This review outlines what is currently known about its composition and capacity in high-income countries and aims to provide an evidence base for effective strategic workforce planning and policy development to address this challenge.

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Table 1. Table of included study characteristics (n=162 unique studies)

Year	Number of results (%) (n=162)
2010-2011	6 (3.7)
2012-2013	22 (13.6)
2014-2015	36 (22.2)
2016-2017	58 (35.8)
2018-2019	40 (24.7)
Geographical focus	
North America	101 (62.3)
Europe	32 (19.8)
Mixed	11 (6.8)
Australia & New Zealand	10 (6.2)
Asia	6 (3.7)
Other	2 (1.2)
Type of provider	
Genetics providers	81 (50.0)
Non-genetics providers	48 (29.6)
Mixed (genetics and non-genetics providers)	30 (18.5)
Not applicable	3 (1.9)
Clinical focus	
Mixed	52 (32.1)
Cancer	42 (25.9)
Not reported	13 (8.0)
Not applicable	13 (8.0)

Genome-wide sequencing	13 (8.0)
Other	12 (7.4)
Prenatal	8 (4.9)
Cardiac	5 (3.1)
Pharmacogenomics	4 (2.5)
Study type	
Cross sectional study	72 (44.4)
Mixed methods	19 (11.7)
Qualitative	17 (10.5)
Prospective cohort	16 (9.9)
Health services or workforce report	12 (7.4)
Other	9 (5.6)
Review	7 (4.3)
Quality improvement study	5 (3.1)
Retrospective cohort	5 (3.1)

Table 2. List of genetics-related tasks performed by healthcare providers, by stage of clinical encounter

Preparation Tasks	Pre-test Appointment Tasks	Post-test Appointment Tasks	Follow-up Tasks	Other Tasks
<ul style="list-style-type: none"> • Obtain and review records • Collect family history information • Literature review • Risk assessment • Test preparation • Test coordination • Case review with other providers • Insurance related tasks • Targeted appointment prep (visual aids, identify support groups etc.) • Triage call • Administrative tasks 	<ul style="list-style-type: none"> • Contracting • Collect information (medical, family, social, pregnancy histories) • Provide education/information • Provide counselling • Facilitate decision making • Facilitate informed consent • Risk assessment • Obtain and review records • Management tasks • Physical exam • Test coordination • Insurance related tasks • Appointment logistics • Making or clarifying a diagnosis 	<ul style="list-style-type: none"> • Obtain and review records • Literature review • Risk assessment • Variant interpretation • Case review with other providers • Results disclosure • Provide education/information • Provide counselling • Management tasks • Follow up- available for support • Follow up- available for education/information • Making or clarifying a diagnosis 	<ul style="list-style-type: none"> • Case review with other providers • Management tasks • Test preparation • Test coordination Cascade testing coordination • Documentation • Insurance related tasks • Administrative tasks • Literature review • Risk assessment • Document family history • Follow up- available for support • Follow up- available for education/information • Obtain and review records • Appointment logistics • Provide counselling 	<ul style="list-style-type: none"> • Case review/educational rounds • Insurance inquiries • Administrative tasks • Teaching students • Supervision of students • Professional development • Research-related tasks • Volunteer activities • Peer supervision

Note: Some tasks appear in more than one column because they may be performed at different time points during the clinical encounter.

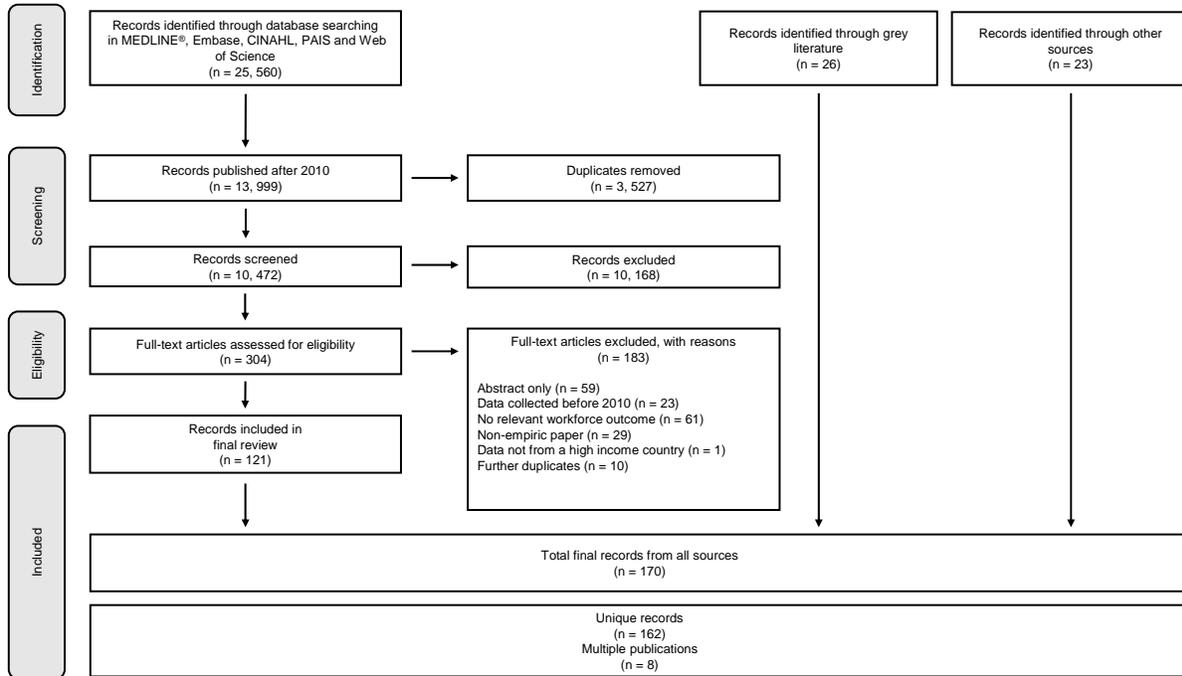


Figure 1. PRISMA flowchart of study selection process.

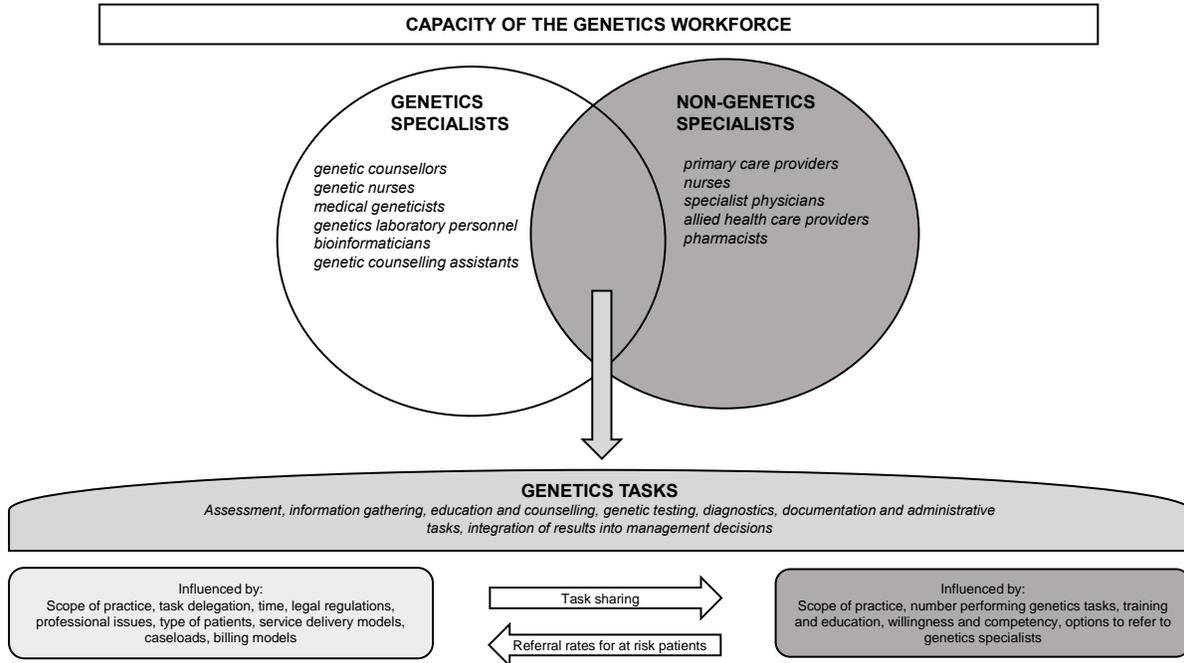


Figure 2. Concept map of the capacity of the genetics workforce. We define genetics-related tasks as any tasks that are related to identifying, assessing, counselling, testing, or diagnosing an individual or their family members with a genetic disorder. We included non-genetics providers who were performing any of the above listed genetics tasks.