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PRACTICE GUIDELINE

National Society of Genetic Counselors WILEY

An evidence-based practice guideline of the National Society of Genetic Counselors for telehealth genetic counseling

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Abstract

There are currently no practice guidelines available for genetic counseling using telehealth modalities. This evidence-based practice guideline was developed in response to increasing use of alternative service delivery models for genetic counseling, specifically telephone and video-based genetic counseling (telehealth genetic counseling or THGC). A recent systematic evidence review (SER) compared outcomes of THGC with in-person genetic counseling and found that for the majority of studied outcomes, THGC was a non-inferior and comparable service delivery model. The SER results were used to develop this guideline. The current and anticipated future use of THGC, including the influence of the COVID-19 pandemic, provides the context for this guideline. Recommendation: The Telehealth Practice Guideline author workgroup conditionally recommends telehealth genetic counseling, either via telephone or video, as a delivery method for genetic counseling. Depending on factors unique to individual healthcare systems and provider and patient populations, THGC may be the only service delivery model available or may be utilized in addition to other service delivery models including in-person genetic counseling. The evidence shows large desirable effects, minor undesirable effects, and increased equity for patients when THGC is available. THGC may reduce or remove existing barriers to patient access to genetic counseling, such as medical conditions and/or disabilities that may affect a patient's ability to travel, inflexible work or school schedules, and lack of reliable transportation, finances, or dependent care. THGC is likely acceptable to key groups impacted by its use and is feasible to implement. Certain patient populations may require additional resources or encounter more barriers in using telemedicine services in general. For these populations, THGC can still be a valuable option if solutions are available.

KEYWORDS
genetic counseling, guideline, service delivery model, telegenetics, telehealth, telemedicine, virtual care

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Sarah Green and Deborah Hartzfeld should be considered joint first author.

1 | INTRODUCTION

What is known about this topic

Genetic counselors have increasingly used alternative service delivery models in recent years, with rapid adoption of telehealth most recently due to the COVID-19 pandemic. A 2021 systematic-evidence review found that telehealth genetic counseling (telephone or video) was generally non-inferior or comparable with in-person genetic counseling.

What this paper adds to the topic

No evidence-based practice guidelines were available for telehealth genetic counseling. This evidence-based practice guideline was developed in response to increasing use of alternative service delivery models for genetic counseling, specifically telephone and video. Current and anticipated future use of THGC, including the influence of the COVID-19 pandemic, provides the context for this guideline.

Knowledge of genetic conditions and availability of genetic testing continue to expand at a rapid rate. It is estimated that 25–30 million individuals in the United States have a rare disease (defined as <200,000 affected), with the majority of those diseases expected to have genetic etiologies (National Human Genome Research Institute, 2020b). Additionally, our understanding about the genetic contribution to more common conditions, such as cardiovascular disease, cancer, diabetes mellitus, Alzheimer's disease, and depression, continues to improve (Jiang et al., 2021; National Human Genome Research Institute, 2020a; U.S. National Library of Medicine Medline Plus, 2021). With approximately 5,200 certified genetic counselors as of March 2021 (American Board of Genetic Counseling, personal communication, July 6, 2021) and 1,240 medical geneticists in the United States as of April 2020, there is concern about a scarcity of genetics providers to meet increasing demand for genetics services (U.S. Government Accountability Office, 2020). A 2017 study showed that the need for genetic counseling had surpassed the available genetic counseling workforce, which they estimated could be remedied by approximately 2024–2030 by increasing the number of genetic counselors entering the workforce (Hoskovec et al., 2018).

Genetic counselors have increasingly shown interest in telehealth to help address issues such as increasing demand, lack of access to care, and healthcare disparities (Boothe et al., 2021; Greenberg et al., 2020; Khan et al., 2021; Zierhut et al., 2018). Telehealth has the potential for a larger impact in patient populations who have significant barriers to in-person visits or have limited local access to specialists (National Conference of State Legislatures Partnership Project on Telehealth, 2015). Approximately 16% of medical geneticists and 20% of genetic counselors reported using telemedicine in a 2015 survey of genetics professionals (Maiese et al., 2019). In early 2020 prior to COVID-19 pandemic-related lockdowns, the National Society of Genetic Counselors (NSGC) administered a professional status survey, which found that approximately half of respondents used more than one service delivery model in 2019, with 95% using in-person appointments, 36% using telephone, and 28% using video (National Society of Genetic Counselors, 2020).

While a minority of providers have used telehealth for many years, the COVID-19 pandemic necessitated rapid adoption of telehealth for genetic counseling, as with many other medical services. Annual data from the federally funded Regional Genetics Networks (RGNs) demonstrate an increase in the number of patients receiving genetics services via telehealth in RGN-supported clinics (not specifically genetic counseling) from 870 patients (June 2017 through May 2018) to 10,082 patients (June 2019 through May 2020, including effects from COVID-19), which is a 1,059% increase (National Coordinating Center for the Regional Genetics Networks, 2021). Increased reliance on telehealth in the future is expected due to progression in telehealth capabilities, consumer demand and the possibility of future disruptions of traditional healthcare service delivery models.

Because of the COVID-19 pandemic, federal and state waivers removed some reimbursement and licensure barriers for telehealth (Centers for Medicare & Medicaid Services, 2021; Federation of State Medical Boards, 2021). Many genetics providers have expressed an intention to maintain telegenetics or THGC as part of their clinical practice, and many patients have expressed a desire for this option to remain available (Bergstrom et al., 2021; Pagliazzi et al., 2020; Reding, 2021; Shur et al., 2021). Additionally, some increased coverage for telehealth services has been made permanent (Lacktman et al., 2021), and some payors are advocating for additional permanent telehealth options (America's Health Insurance Plans, 2020). Current and anticipated future use of THGC provides the context for this guideline.

A variety of terms have been used to describe the process of providing patient care via telephone, interactive video, or other methods that are not in-person. For the purposes of this guideline, we will use the term telehealth genetic counseling (THGC) to refer to either telephone or video-based genetic counseling. This definition of THGC is used independently of terms used by other publications, organizations, or payors and is not meant to replace or contradict other terminology.

The NSGC and the American College of Medical Genetics and Genomics (ACMG) have made efforts to provide telehealth resources to their members through blogs, webinars, online courses, and conference sessions both before and during the COVID-19 pandemic. Many medical specialty organizations have published positions, policies, or guidelines on telehealth applications within their specialties. However, there are currently no practice guidelines available specifically for genetic counseling using telehealth modalities. Danylchuk et al. (2021) recently published a systematic-evidence review (SER) showing that telephone and video-based genetic counseling is a non-inferior and comparable service delivery model to in-person genetic counseling based on available data. The SER results provided a majority of the data used in the development of this practice guideline.

2 | METHODS

2.1 | Group composition and conflicts of interest

The author workgroup was selected by the NSGC Practice Guidelines Committee (PGC) beginning in 2017. NSGC solicited members via email requesting applications for both the systematic-evidence review (SER) and practice guideline (PG) author workgroups. Interested applicants sent a CV and statement of interest. The initial PG author workgroup consisted of eight genetic counselors. Prior to completion of the SER and initiation of author group work, three genetic counselors stepped down and three new members were selected by NSGC using the same process. No judgments about the evidence were made prior to the convening of the current author workgroup in May 2020.

The final author workgroup consists of eight certified genetic counselors with experience providing THGC services. A medical oncologist (JS) and patient representative (SF) from advocacy group Facing Our Risk of Cancer Empowered (FORCE) were recruited from networking conducted by the author workgroup and NSGC outreach. JM served as methodologist (non-voting) for the overall project starting in April 2019 and with the PG author workgroup in May 2020.

National Society of Genetic Counselors requires systematic evidence review, practice guideline, and practice resource authors to complete a conflict of interest (COI) disclosure survey annually, starting at the formation of the author workgroup. Authors must also report interim COI changes to the NSGC Practice Guideline Committee (PGC) within 30 days.

The PGC categorizes COI into two tiers. Tier 1 COI includes any direct, personal financial benefit that is ongoing or within the previous 12 months from a commercial entity that may benefit from the document. Tier 1 COI includes research funding from a commercial entity for 25% or greater of an author's salary. Tier 2 COI includes limited consultant roles, paid stipends/travel, and ongoing consultancy roles with companies that are involved in healthcare but may not directly benefit from the document.

The PGC assesses the overall balance of COI for the author workgroup and requires that no more than 40% of authors have Tier 1 COI and no more than 80% have either Tier 1 or Tier 2 COI. Lead authors must be free of Tier 1 COI for the entirety of the development of the document and can only have Tier 2 COI if serving alongside a co-lead author with no Tier 1 or Tier 2 COI.

A change in COI resulted in an imbalance of members with Tier 1 COI in January 2021. As a result, one genetic counselor agreed to being released from the author workgroup to satisfy COI requirements.

2.2 | Evidence base

The primary evidence base consists of the SER (Danylchuk et al., 2021). The original PG author workgroup and the SER workgroup members convened to identify the overarching clinical question and specify the populations, intervention, comparator, outcomes, and timing (PICOTS) of interest (Table 1).

TABLE 1 PICOTS for telehealth genetic counseling SER from Danylchuk et al. (2021) (reprinted with permission)

Population	Patients receiving genetic counseling for initial or follow-up appointments Genetic counselors delivering genetic counseling via videoconferencing or telephone
Intervention	Genetic counseling delivered via videoconferencing or telephone
Comparator	In-person genetic counseling
Outcomes	Patient-centered, provider-centered, access to care
Timing/setting	Outpatient setting

The SER was conducted using methods detailed in Danylchuk et al. (2021). Briefly, the SER workgroup, with input from the PG author workgroup and the aid of a medical librarian, developed a search strategy for several databases, including MEDLINE, Cochrane, CINAHLPlus, PsycINFO, and Web of Science. SER workgroup members screened the peer-reviewed literature published up to June 24, 2019 and reviewed potentially relevant articles in full according to a priori developed inclusion and exclusion criteria. Reviewers extracted data and assessed the risk of bias for each included study. All phases of the SER were performed in duplicate, by blinded reviewers; conflicts were resolved through discussion or by a third reviewer (Danylchuk et al., 2021).

As the literature on telehealth modalities expanded significantly during the COVID-19 pandemic, members of the PG author workgroup did an additional search for peer-reviewed literature published after June 24, 2019, through January 11, 2021 under the direction of the methodologist, adhering to the SER protocols. Articles identified in the updated literature search were shared with the SER workgroup to update their SER and inform the PG author workgroup. Detailed methods, including the search query used for OVID MEDLINE, are provided in Supplementary Material of Danylchuk et al. (2021). Given the rapidly evolving nature of the evidence base, the PG author workgroup also reviewed all abstracts presented at the NSGC Annual Conference, 2020, for outcomes pertaining to THGC. Further, the PG author workgroup directly sought unpublished data from organizations known to perform THGC during the COVID-19 pandemic for consideration. These organizations were ones known to members of the PG author workgroup.

2.3 | Data synthesis and the certainty of the evidence

From 947 articles screened, 42 articles encompassing more than 13,000 patients were selected for inclusion in the SER (Danylchuk et al., 2021). The SER workgroup results were provided to the PG author workgroup for review. For each outcome, certainty of the evidence was based on the overall risk of bias of included studies, inconsistency (heterogeneity between studies), indirectness of the evidence to align with the PICOTS, and imprecision of the results.

Overall certainty of the evidence for each outcome was reported as one of the following: high, moderate, low, or very low.

2.4 | GRADE process

The GRADE (Grading of Recommendations Assessment, Development and Evaluation) Evidence to Decision (EtD) framework was used in development of the recommendation (Moberg et al., 2018). The PG author workgroup prioritized outcomes as critical, important, or not important to make a recommendation based on a nine-point scale, where 1–3 were considered not important for the recommendation, 4–6 were important, and 7–9 were critical. Importance rankings do not reflect the inherent value of an outcome, but rather the importance of the outcome for developing this guideline. The first prioritization vote was made by online poll. Consensus was reached via video conference calls with 80% consensus for each outcome. Dissenting perspectives were documented.

The following outcomes were prioritized as critical: patient psychosocial, decision-making, patient attendance (initial and follow-up), convenience/travel (patient time and costs), patient trust and rapport with genetic counselor, and access to care. The following were prioritized as important: health behaviors (intent to/uptake of), client satisfaction, facilitation of genetic testing, patient knowledge, and wait time for appointment/results disclosure. The following outcomes were rated as not important: patient preference for delivery method, provider satisfaction, provider perceived/actual disadvantages of THGC, and provider workflow issues (Table 2).

The PG author workgroup followed the GRADE EtD Framework, which includes 12 domains. In addition to the desirable and undesirable effects of the intervention and balance of these effects, PG members considered the priority of the problem, overall certainty of the evidence, patient values, impact to health equity, acceptability of the intervention to relevant groups, cost-effectiveness, and feasibility of implementation to inform the strength and direction of the recommendation. For domains in which no peer-reviewed evidence was identified and reported in the SER by Danylchuk et al. (2021), additional searches for peer-reviewed articles, conference abstracts or proceedings published in 2021, and economic analyses were sought.

Summaries of the peer-reviewed evidence and additional considerations (i.e., non-peer reviewed evidence and clinical/patient experiences) for each EtD domain were documented in a table in a shared Google Drive that each PG workgroup member had access to at all times. Judgments for each EtD domain were made during conference calls with the workgroup. Votes were obtained verbally or written as needed, with at least 80% agreement required to finalize a domain judgment. Dissent of any workgroup member unable to be resolved through discussion was documented with their rationale.

2.5 | Draft recommendation

The draft recommendation was reviewed and revised by the PG author workgroup. Unanimous agreement was obtained for the final recommendation statement (strength and direction). Using GRADE methodology, a strong recommendation reflects the guideline panel's confidence that the desirable effects of adhering to the intervention outweigh the undesirable effects and can be interpreted as a recommendation that most patients would want the recommended intervention to be offered and very few would not.

TABLE 2 Genetic counseling outcome rankings by importance

Outcome	Importance ranking	Certainty of the evidence
Access – attendance (initial attendance and follow up)	8	High
Access – travel (time and travel-specific costs)	8	Moderate
Access – convenience	8	High
Patient psychosocial	8	Low
Decision-making	8	High
Access (cost of counseling, testing)	7	Moderate
Client trust and rapport	7	High
Client satisfaction	6	Low
Health behaviors	6	High
Access – wait time for appointment/result disclosure	5	High
Patient knowledge	5	Low
Genetic testing	5	Very low
Patient preference for delivery method	3	Very low
Provider perceived/actual disadvantages	3	Very low
Provider satisfaction	3	Moderate
Provider workflow	2	High

Note: Importance rankings: 1–3 = not important, 4–6 = important, 7–9 = critical.

A strong recommendation suggests a policy that can be adopted in most instances and for which clinicians would agree that most patients should be offered the intervention. A conditional recommendation indicates that the guideline panel determined the desirable effects probably outweighed the undesirable effects, but the certainty is not high and can reflect significant differences in the balance of effects in some situations where the guideline may be implemented. It can be interpreted as a recommendation that there may be a larger group of individuals that would not want the intervention and that development of a policy may require significant debate and the involvement of relevant key groups impacted by the guideline. A draft guideline manuscript was prepared by the workgroup co-lead authors and was iteratively revised by the full PG author workgroup.

2.6 | External review process

The guideline manuscript underwent external peer review through the standard peer-review process at the *Journal of Genetic Counseling*. In addition, a draft of the manuscript was reviewed and critically appraised by NSGC membership, the NSGC Practice Guideline Committee, the NSGC Ethics Advisory Group, NSGC Legal Counsel, and the NSGC Board of Directors. The PG author workgroup's co-lead authors and the methodologist revised the manuscript in response to external peer-review comments and those from the above NSGC reviews. Changes to the recommendation statement were required to be unanimously accepted by the full PG workgroup.

3 | RECOMMENDATION

The Telehealth Practice Guideline author workgroup conditionally recommends telehealth genetic counseling, either via telephone or video, as a delivery method for genetic counseling. Although data is lacking regarding resources required and cost-effectiveness, THGC is expected to be feasible to implement and likely acceptable to key groups impacted by its use. Depending on factors unique to individual healthcare systems and provider and patient populations, THGC may be the only service delivery model available or may be utilized in addition to other service delivery models including in-person genetic counseling. For many genetic counseling providers, THGC became a routine part of care during the COVID-19 pandemic.

4 | RATIONALE

Based on reviewed evidence, we conclude that THGC has large desirable effects, minor undesirable effects, and likely increases equity to patients. We concluded there was probably no important uncertainty or variability about how patients value the important and critical genetic counseling outcomes. Additionally, we conclude THGC is likely acceptable to key groups impacted by its use and is feasible to implement. Key groups identified include patients, genetic counseling providers, other healthcare providers, payors, and healthcare systems. The GRADE summary of judgments is available online as a Supplementary Material. The conditional strength of the recommendation is influenced by the lack of current data regarding resources required and cost-effectiveness for THGC, as well as considerations of acceptability and health equity specific to THGC. These gaps in data are expected to decrease over time as more experiences with THGC are published.

For the majority of outcomes studied by Danylchuk et al. (2021), THGC was non-inferior or comparable with in-person genetic counseling, including uptake of genetic testing, health behaviors, psychosocial parameters (anxiety, depression, worry, stress/distress, and general quality of life, function, or well-being), knowledge, satisfaction, and decision-making. Additionally, they noted that THGC is more convenient and associated with lower cost and less travel for patients than in-person genetic counseling.

Regarding outcomes ranked as critical by the PG workgroup, the certainty of evidence that THGC is non-inferior was high for patient decision-making, trust and rapport, attendance, and convenience (Danylchuk et al., 2021). Psychosocial outcomes had low certainty due to inconsistency and imprecision; however, genetic counseling by any method studied (in-person, telephone or video) reduced worry, distress, and depression (Danylchuk et al., 2021).

Critical access outcomes associated with time and cost for genetic counseling, testing, and travel had moderate certainty of evidence due to imprecision with included studies (Danylchuk et al., 2021). For purposes of creating this guideline, convenience and travel (time and cost) were merged into a single outcome.

Important outcomes with high certainty include health behaviors and wait time (Danylchuk et al., 2021). Important outcomes of knowledge and satisfaction outcomes had low certainty, with genetic counseling resulting in improved knowledge and improved satisfaction regardless of method. Satisfaction for THGC was non-inferior to in-person, although data showed that patient satisfaction scores were higher for video vs. telephone genetic counseling (Danylchuk et al., 2021). Facilitation of genetic testing had very low certainty due to heterogeneity between studies, with randomized-control trials showing non-inferiority and observational studies having mixed results with some showing lower uptake of genetic testing with THGC, and others showing no difference (Danylchuk et al., 2021).

5 | FEASIBILITY AND IMPLEMENTATION

Telehealth genetic counseling was determined to be a feasible and likely acceptable service delivery model for the identified key groups. As with all new technology-driven care modalities, there are challenges to implementation that require further research and development of data-driven best practices.

5.1 | Impact on health equity

We anticipate health equity will likely increase with the use of THGC because it can reduce many of the barriers associated with attending in-person appointments, including geographic and financial factors (Centers for Disease Control and Prevention, 2020; National Conference of State Legislatures Partnership Project on Telehealth, 2015). One example of increased health equity in THGC is a study sponsored by the Foundation Fighting Blindness to provide genetic counseling and genetic testing services via telephone to individuals with low vision (Alastalo et al., 2020). Community-level physicians were engaged to offer appropriate patients an option to receive genetic counseling locally or by telephone for inherited retinal disease. More than 90% of 188 participating providers chose to utilize telehealth-based genetic counseling services, and >97% of patients reported satisfaction with the telephone-based genetic counseling they received (Alastalo et al., 2020).

However, there is concern that telehealth could increase health disparities for certain populations and could worsen the divide in digital equity (American Telemedicine Association CEO's Advisory Group on Using Telehealth to Eliminate Disparities and Inequities, 2021; Nouri et al., 2020; Rodriguez et al., 2020; Sheon, 2021). Efforts to anticipate, recognize, and address health disparities, including digital equity, in the implementation of telehealth, are imperative (American Telemedicine Association CEO's Advisory Group on Using Telehealth to Eliminate Disparities and Inequities, 2021; Nouri et al., 2020; Rodriguez et al., 2020; Sheon, 2021; Siegel & Volk, 2021; Uhlmann et al., 2021).

Digital equity is defined as an individual or community having the information technology capacity to fully participate in society, democracy, and the economy (National Digital Inclusion Alliance, n.d.). Per a 2019 survey, there is a marked difference in digital equity between people who have lower versus higher incomes (Vogels, 2021). In this survey, approximately 25% of adults with household incomes under $30,000 annually reported they do not have a smartphone, 44% do not have broadband services, and 46% do not own a computer. Of those who do have a smartphone, 26% are ‘smartphone-dependent’ and are only able to access the internet through their cell phone plan. To help reduce this disparity during the COVID-19 pandemic, in February 2021, the Federal Communications Commission approved an emergency broadband benefit program to help qualified households obtain internet access and internet-accessible devices (Federal Communications Commission, 2021).

Equity was also a motivator of telephone appointments becoming more widely accepted as billable visit types during the pandemic (Center for Connected Health Policy, 2021). Some healthcare systems widely or even preferentially used telephone appointments because they recognized video technologies would be prohibitive to their patient population (Mauer et al., 2021). Though telephone is more accessible to some patient populations, this should not prohibit the promotion of equal access for all telehealth modalities including telephone and video (Rodriguez, Betancourt, et al., 2021). Reimbursement for and use of telephone appointments could decrease if state and federal waivers allowing telephone services expire.

5.2 | Acceptability to key groups impacted by THGC

Within the GRADE framework, acceptability depends upon many factors, including benefits, harms, costs, and how different key groups or participants value those parameters (Moberg et al., 2018). While there was no peer-reviewed evidence regarding acceptability in this context, THGC was determined likely acceptable to key groups by considering available evidence for benefits, harms, variability in the value of the main outcomes, and impact on health equity (Supplementary Material).

Additionally, key groups have shown interest in the continued use of telehealth. Many genetics providers and patients have expressed a desire for the continued use of telegenetics or THGC (Bergstrom et al., 2021; Pagliazzi et al., 2020; Reding, 2021; Shur et al., 2021). A March 2021 survey of 2,000 American adults found that almost 88% want to continue using telehealth post-COVID-19 pandemic for non-urgent appointments (Sykes, 2021). More than half (56%) of hospital and health system leaders say they are planning to increase their investment in telemedicine during the next 2 years, according to a survey from telehealth vendor Amwell and HIMSS Analytics (Siwicki, 2021).

Previously, insurance coverage and reimbursement for telehealth appointments were inconsistent, impacting cost to the patient, which may influence acceptability of THGC (Lacktman et al., 2021; National Conference of State Legislatures Partnership Project on Telehealth, 2015; Zierhut et al., 2018). Due to the COVID-19 pandemic, telehealth coverage became more widespread, with many states making permanent changes to their telehealth policies (Lacktman et al., 2021; Volk et al., 2021). Additionally, some payors are advocating for further permanent telehealth options (America's Health Insurance Plans, 2020). However, reimbursement for THGC, and for genetic counseling services in general, remains a prominent issue and is discussed further in the reimbursement barriers section (Mills et al., 2021; Richardson, 2020). Insurance coverage for THGC is expected to improve in the future as genetic counseling becomes a well-recognized need to both patients and providers.

5.3 | Access to care

Patient populations who may benefit most from THGC include, but are not limited to, individuals who have difficulty traveling to clinic, live in rural or underserved areas with no local access to genetic counseling, or have long wait times for a genetic counseling appointment (Centers for Disease Control and Prevention, 2020; Uhlmann et al., 2021). People with disabilities and/or conditions that affect their medical, mental, or behavioral health can experience more difficulty attending in-person clinic visits and can potentially benefit from telehealth options (American Association of People with Disabilities, n.d.; Annaswamy et al., 2020; Ballantyne et al., 2019; Noel & Ellison, 2020; Valdez et al., 2021; Young & Edwards, 2020). Other general barriers that may be ameliorated by telehealth include conflicting work or school schedules and lack of reliable transportation, finances, or dependent care (National Conference of State Legislatures Partnership Project on Telehealth, 2015). Many traditional in-person genetics clinics are located at academic institutions in more metropolitan areas, with lack of genetics services in rural areas (U.S. Government Accountability Office, 2020). The Centers for Disease Control and Prevention (CDC) and the U.S. Department of Veterans Affairs (VA) systems have similarly recognized these types of patient characteristics as reasons to support telehealth (Centers for Disease Control and Prevention, 2020; U.S. Department of Veterans Affairs, 2016). Additionally, if the need for physical clinic space is eliminated through the adoption of THGC, patient volume could potentially increase and would be determined by other factors such as provider availability.

5.4 | Patient barriers

Certain patient populations may encounter more barriers using THGC or telemedicine services in general. Individuals who may experience greater barriers include, but are not limited to, those with low digital or health literacy; reduced or unreliable access to telephones, telephone service, internet, data plans or video-capable devices; no insurance coverage for THGC; or those who use an interpreter for spoken language or sign language (Noel & Ellison, 2020; Nouri et al., 2020; Rodriguez et al., 2020; Rodriguez, Saadi, et al., 2021; Sheon, 2021; Uhlmann et al., 2021). Some of these barriers were highlighted by a study of Medicare beneficiary use of telehealth (Chang et al., 2021). Barriers to THGC may differ depending on modality (telephone vs. video). For example, video calls may be challenging to those with low technology literacy or low vision, but telephone encounters likely present less of a barrier. Additionally, some individuals may avoid telehealth services for a variety of reasons such as concerns about privacy and confidentiality or trust in the efficacy of telehealth (Hall & McGraw, 2014; Lam et al., 2020; National Conference of State Legislatures Partnership Project on Telehealth, 2015; Shachar et al., 2020).

Telehealth can present new challenges for some individuals with disabilities (Annaswamy et al., 2020; Valdez et al., 2021; Young & Edwards, 2020). Individuals with disabilities have legal protection for their rights to access telehealth fully and equally or have equally effective options available to them (U.S. Department of Health and Human Services, 2021a). Information, guidelines, and tip sheets have been developed by various organizations addressing potential barriers for individuals with disabilities such as the Health Resources and Services Administration (Health Resources and Services Administration, 2021), the American Psychological Association (American Psychological Association, 2014), the Hearing Loss Association of America (Hearing Loss Association of America, 2020), and the ANCOR Foundation and United Cerebral Palsy (ANCOR Foundation, United Cerebal Palsy, 2021). Noel and Ellison (2020) proposed the term 'inclusive innovation' to describe the thoughtful and purposeful inclusion of people with disabilities in forward advancements of telehealth.

Provision of spoken language and sign language interpreters is common, especially in well-established clinics associated with tertiary care centers and in regions where a significant portion of the population has a non-English first language. Interpreter services can often be adapted to a telephone or video-based model. Barriers to provision of interpreter services are likely unique to the institution, geographic location, or type of video connection software, and efforts should be made to address these barriers to provide equal access to services (Health Resources and Services Administration, 2021).

Some patients may struggle with telehealth technology, particularly individuals those with low digital literacy or limited access to computers or smartphones (Health Resources and Services Administration, 2021; Sheon, 2021; Vergouw et al., 2020). Various strategies, which will depend upon the characteristics of the patient population, can be implemented to reduce the number of patients who have difficulty using telehealth (Sheon, 2021). Providers currently have multiple options for user-friendly HIPAA-compliant video connections (U.S. Department of Health and Human Services, 2021b), with patient preferences and ease of use being important considerations. Anecdotally, patients may have trouble with issues such as controlling volume or switching camera views, but if a provider is familiar with the application, minor issues can often be remedied with minimal time and effort. Technical issues such as dropped or poor connections are unavoidable and require continued improvement efforts but are likely becoming less common (Patel et al., 2021).

Many barriers to video visits can be ameliorated if telehealth is used in a clinic-to-clinic setting with staff on hand at the patient site if resources and space are available. Clinic-to-clinic connections do not require independent technology use by the patient. Some novel telehealth models are being implemented by the VA. For Veterans living in broadband-poor areas or with long travel times to the VA, the Accessing Telehealth through Local Area Stations (ATLAS) pilot offers Veterans the option of private telehealth-equipped appointment space furnished with high-speed internet, telehealth compatible technology, and an on-site attendant to assist (U.S. Department of Veterans Affairs, n.d.). Through this pilot initiative, VA has partnered with Philips, Walmart, Veterans of Foreign Wars (VFW), and The American Legion. Local libraries are also facilitating telehealth in many communities (Settles & EveryLibrary Institute, 2021).

Telehealth genetic counseling may not be a suitable solution for all types of encounters, such as those where in-person services are needed in conjunction with genetic counseling. In-person requirements may include physical exams, procedures, non-genetic laboratory testing, or genetic testing. Many types of genetic testing labs have expanded sample collection options, such as saliva or buccal samples, which can be collected at home by the patient. Additionally, some labs offer mobile phlebotomy services. Some studies suggest lower test completion rates with patient-driven collection methods compared with in-clinic blood draws (Shannon et al., 2021). Inability to collect a sample at the time of appointment introduces an additional barrier to test completion (Bergstrom et al., 2021). Lack of test completion and sample collection errors by patients at home (e.g., eating/drinking prior to collection, not getting enough sample, mislabeled or unclosed tubes) can lead to sample failure and delay test processing (Mauer et al., 2021).

5.5 | Provider barriers

Genetic counselors may have difficulty providing telephone and video genetic counseling due to insurance reimbursement, state licensure laws, and workflow issues (Bergstrom et al., 2021; Boothe et al., 2021; Bradbury et al., 2016; Khan et al., 2021; Lea et al., 2005; Mills et al., 2021; National Society of Genetic Counselors, 2021; Reding, 2021; Shannon et al., 2021; Zierhut et al., 2018). These concerns are discussed in more detail in the sections on reimbursement and healthcare institution barriers.

Some genetic counselors feel providing psychosocial support is more difficult over telephone or video and specifically note loss of nonverbal cues and visual aids as a challenge (Mills et al., 2021; Turchetti et al., 2021; Zierhut et al., 2018). The well-documented success of mental health telehealth provides reassurance that empathic connection is feasible by telehealth (Thomas et al., 2021).

Genetic counselors often use visual aids during in-person appointments to demonstrate genetic concepts. Use of visual aids may require more effort in a telehealth setting (Mills et al., 2021; Turchetti et al., 2021). Depending on the platform, video appointments with screen sharing options could increase the ease and flexibility of using visual aids. Sharing images or videos can be done in real time or asynchronously, as demonstrated in a recent study on asthma action plans (Hamour et al., 2020). Genetic counselors are generally adept at providing written summaries with relevant diagrams as needed.

5.6 | Reimbursement barriers

Billing for services in the United States remains a concern for many genetic counselors and institutions and is dependent on state laws, licensure status, employer practices, and insurance reimbursement policies (Bergstrom et al., 2021; Boothe et al., 2021; Bradbury et al., 2016; Lea et al., 2005; Mills et al., 2021; National Society of Genetic Counselors, 2021; Zierhut et al., 2018). In some cases, billing for THGC services may not be possible even for genetic counselors who are able to bill for in-person visits (Mills et al., 2021). Depending on relevant regulations, reimbursement may depend on the type of communication utilized in the visit (e.g. telephone not billable while video is) (Center for Connected Health Policy, 2021; Lacktman et al., 2021).

Restrictions making in-person billing prohibitive will make billing for THGC difficult, as well. Private payors have policies unique to their plans, but in general provide some coverage for genetic counseling. At the time this guideline was written, U.S. Centers for Medicare and Medicaid Services (CMS) does not reimburse genetic counselors independently or allow them to provide telehealth services under the COVID-19 emergency declaration blanket waiver (Centers for Medicare & Medicaid Services, 2021; Richardson, 2020).

The extent to which healthcare systems can continue to offer video or telephone appointment options in the future will be greatly influenced by insurance reimbursement policies. America's Health Insurance Providers support the continued and permanent use of telehealth post-COVID-19 pandemic where clinically appropriate and have made recommendations to advocate for telehealth (America's Health Insurance Plans, 2020). Additionally, some increased coverage for telehealth services has been made permanent (Lacktman et al., 2021).

Payor regulations and licensure requirements may limit a genetic counselor's ability to provide THGC based on the geographical locations of the genetic counselor and/or patient (National Society of Genetic Counselors, n.d.; Boothe et al., 2021; Lacktman et al., 2021). As of June 2022, 31 US states had genetic counseling licensure, and three more states were in the process of obtaining licensure (National Society of Genetic Counselors, 2022). Many states had emergency waivers allowing out-of-state providers to provide telemedicine services to patients without licensure in the patient's state, although some of these waivers have already expired, reinstituting the need for licensure in the patient's location during the THGC visit (Federation of State Medical Boards, 2021).

5.7 | Healthcare institution barriers

There have been concerns regarding the security and safety of telehealth and telemedicine platforms (Hall & McGraw, 2014; Shachar et al., 2020). The rapid telehealth expansion due to the COVID-19 pandemic necessitated healthcare institutions and providers to safely and securely provide telehealth services, although some restrictions were relaxed to accommodate the sudden changes (American Telemedicine Association, 2020). Continued advances in technology and telehealth will require evolving safety policies and protocols (Healthcare and Public Health Sector Coordinating Council, 2021; National Consortium of Telehealth Resource Centers, 2019; Virdi, 2021).

The location of the provider must be HIPAA-compliant, and efforts should be made to ensure privacy for the patient's location, as well, although this is ultimately dependent on the patient if they are not located in a clinic setting (American Telemedicine Association, 2014; U.S. Department of Health and Human Services

Office for Civil Rights, 2020). THGC can take place in several different settings with connections from either non-clinic (e.g., home, work, etc.) or clinic spaces of varying types for both the patient and the provider, and the options will often be institution-specific.

While legal issues surrounding telehealth are beyond the scope of this document, institutions/companies should have protocols in the event of an emergency at the patient location so emergency medical services can be dispatched. This may include having the patient enter their geographical location as part of the visit (American Telemedicine Association, 2014). If an illegal or unsafe circumstance is witnessed, these should be reported in accordance with the law and institution policies but may prove to be unique situations in which standard protocols are not yet available (American Telemedicine Association, 2014).

Establishing a well-structured THGC program presents additional challenges in implementation that are outside the scope of this guideline. Support and resources to guide telehealth practice are available from several resources including the Regional Genetics Networks (RGNs), the National Consortium of Telehealth Resource Centers (TRCs), and the American Telemedicine Association (ATA).

6 | LIMITATIONS/FUTURE STUDIES

Limitations of the SER data noted by Danylchuk et al. (2021) include: mostly telephone-based studies, small sample sizes and/or small subgroups, majority of studies were related to cancer specialty, majority of patients identified as non-Hispanic White females, English-language-only studies, moderate or serious risk of bias, or poor-quality studies. These and additional limitations noted below were important considerations in the development of this guideline.

We were unable to assess the resources required to provide THGC due to limited data. Further research is needed in this area, with differentiation between resources required to provide services and resources required by patients to receive services. True resource costs depend on many factors, including but not limited to: computer equipment (including video cameras, microphones, headsets, etc.) for both provider and patient; cell phones and data plans/minutes; the platform through which THGC is facilitated; internet connection/plan; the THGC model (patient at home vs. patient in local clinic office); and the number of personnel involved in delivery of care.

Another limitation is the inability to assess cost-effectiveness, with available studies being mostly outdated. One study found telephone counseling saved $114 per patient compared with in-person care due to less time spent in the counseling session, less patient travel, and lower overhead costs (Schwartz et al., 2014). Economic analyses (not cost-effectiveness studies) varied depending on the model of genetic counseling, date of publication, and costs assumed in the economic model. In general, THGC was observed to be less costly in terms of cost per patient counseled and tested and cost per variant identified in a cancer setting (Buchanan et al., 2015; Chang et al., 2016; Jenkins et al., 2007; Schwartz et al., 2014). Actual costs to provide THGC and the comparison of those costs to in-person care were rarely reported in peer-reviewed studies. Costs varied based on perspective (cost to patient vs. cost to health system/GC) and what was being assessed (care vs. equipment). However, economic analyses of telehealth via video in other settings (mental health and home care) found telehealth can be cost-effective (Wade et al., 2010). Additional data on resources required and cost-effectiveness of THGC may influence acceptability and feasibility of THGC to some degree; therefore, future studies are warranted.

Most of the studies included in the SER were conducted in the United States within the cancer subspecialty of genetic counseling during a time where systems had less experience with telehealth than current patient and provider populations. For a broader perspective, it would be helpful to have more data from other specialty areas and health systems that have different funding mechanisms outside of insurance reimbursement.

More research in diverse populations is important in assessing successes and limitations of THGC. This includes both patients and genetic counselor providers. Lack of diversity in genetic research is well documented (Popejoy & Fullerton, 2016; Sirugo et al., 2019). Inclusion of individuals from varied disability communities, ethnic groups, gender identities, health and digital literacy levels, income levels, and languages is recommended. Efforts to include diverse perspectives in this space require prioritization and resources from healthcare institutions and clinical teams. Recent recommendations have been made for including more diverse populations in research including genetics and genetic counseling, especially given the more recent focus on precision medicine (Claw et al., 2018; Fisher et al., 2020; Halbert & Harrison, 2018; Sabatello, 2018; Wieland et al., 2021).

Further research on workflow outcomes would help define impact on processes and timeliness. A more complete understanding of how telehealth impacts genetic testing processes is one area for future research. Some studies included in the SER suggest lower uptake of genetic testing in THGC compared with in-person (Kinney et al., 2016; Steffen et al., 2017). It would be important to know if difference in modality impacts patient desire for or completion of genetic testing. Inability to collect a sample at the time of appointment introduces an additional barrier to test completion (Bergstrom et al., 2021). While many commercial labs send saliva/buccal kits directly to patients' homes, some institutional policies prohibit this. Lack of test completion and sample collection errors by patients at home (e.g., eating/drinking prior to collection, not getting enough sample, mislabeled or unclosed tubes) can lead to sample failure and delay test processing.

Only 19 of the 42 studies included in the SER evaluated video genetic counseling compared with 31 for telephone genetic counseling. More data on video genetic counseling and how it compares to both in-person genetic counseling and telephone genetic counseling could be useful.

This guideline focuses on telephone and video-based genetic counseling between one provider and one patient/family, but other types of telehealth are becoming increasingly common, such as group THGC, educational videos or webinars, text chat applications, asynchronous telehealth, and artificial intelligence (Kearney et al., 2020). Future guidelines may address these additional telehealth applications as needed.

7 | PLANNED REVIEW/REVISION

Current and evolving evidence-based guidelines are needed and will become increasingly necessary with the continued growth of telehealth and THGC. This guideline should undergo planned review in 18–24 months. A significant amount of relevant literature is expected to be published due to the surge of telehealth services implemented during the COVID-19 pandemic.

8 | CONCLUSION

In summary, the SER found THGC was comparable with in-person genetic counseling for the important and critical outcomes identified by our workgroup. These results were supported by our clinical experience and additional relevant literature. The COVID-19 pandemic resulted in accelerated adoption of telehealth, coinciding with the development of this guideline. This provided a unique perspective on THGC and its future use. We conditionally recommend THGC, either via telephone or video, as a delivery method for genetic counseling. We anticipate changes in the telehealth landscape and a deepening of the literature will provide further evidence about THGC and its potential role as a feasible and acceptable service delivery model for genetic counseling.

DISCLAIMER

The practice guidelines of the National Society of Genetic Counselors (NSGC) are developed by NSGC members to assist genetic counselors and other healthcare providers in making decisions about appropriate management of genetic concerns; including access to and/or delivery of services. Each practice guideline focuses on a clinical or practice-based issue and is published by NSGC for informational and education purposes only.

NSGC is not undertaking to render specific advice. The reader must rely solely on their own judgment to determine what practices and procedures, whether included in the practice guideline or not, are appropriate for them, their patient, their institution, or their practice. State law varies, accordingly, none of the information contained in an NSGC practice guideline should be relied on as a substitute for the laws of the particular state in which the reader practices or the specific policies established by the reader's institution. In addition, variations in practice, which take into account the needs of the individual patient and the resources and limitations unique to the institution or type of practice, may warrant competencies, standards, and/or approaches that differ from the information contained in the practice guideline. The information contained in NSGC's practice guidelines is not intended to displace a genetic counselor or other healthcare provider's best medical judgment based on the clinical circumstances of a particular patient or patient population. NSGC does not 'approve' or 'endorse' any specific methods, practices, or sources of information contained or referenced in its practice guidelines.

The information presented in NSGC's practice guidelines has been obtained from current professional literature and other sources believed to be reliable at the time. As such, information within any particular practice guideline reflects the current scientific and clinical knowledge at the time of publication, is only current as of its publication date, and is subject to change without notice as advances emerge.

This guideline represents the views of the authors. It does not necessarily represent the official views or positions of their affiliated institutions and is not necessarily an endorsement by their affiliated institutions, including but not limited to HRSA, HHS, or the U.S. Government.

AUTHOR CONTRIBUTIONS

Sarah Green: Conceptualization; writing – original draft; writing – review and editing. **Deborah EH Hartzfeld:** Conceptualization; writing – original draft; writing – review and editing. **Alissa Bovee Terry:** Conceptualization; writing – original draft; writing – review and editing. **Kristi Fissell:** Conceptualization; writing – review and editing. **Sue Friedman:** Conceptualization; writing – review and editing. **Nicholas Paolino:** Conceptualization; writing – review and editing. **Kate Principe:** Conceptualization; writing – review and editing. **John Sandbach:** Conceptualization; writing – review and editing. **Karmen Trzupek:** Conceptualization; writing – review and editing. **Stephanie Winheld:** Conceptualization; writing – review and editing. **Jennifer Malinowski:** Conceptualization; methodology; software; supervision; writing – review and editing. All authors participated in the GRADE Evidence to Decision process for prioritizing outcomes and voting on judgements. Sarah Green and Deborah Hartzfeld drafted the manuscript. All authors gave final approval of this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

Sarah Green, Deborah Hartzfeld, John Sandbach and Sue Friedman declare they have no conflict of interest. Alissa Bovee Terry received salary support from the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). Karmen Trzupek and Stephanie Winheld are employees of Informed DNA. Kristi Fissell is an employee of Integrated Genetics. Nicholas Paolino is an employee of CooperSurgical. Kate Principe has received speaker honorarium from Invitae, Bio-Rad and US Oncology/McKesson. Jennifer Malinowski served as the contract methodologist and has no other conflicts to disclose.

HUMAN STUDIES AND INFORMED CONSENT

This practice guideline did not include human subject research.

ANIMAL STUDIES

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

DATA SHARING AND DATA ACCESSIBILITY

No original data have been used for this practice guideline manuscript.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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