

# An Introduction to the Genetic Counseling Business Case Experience

Learnings from NSGC's First Business Case Summit

—— **2021**

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# MAIN TAKEAWAYS

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Genetic counselors generally have knowledge gaps that lead to billing and reimbursement inconsistencies in the field



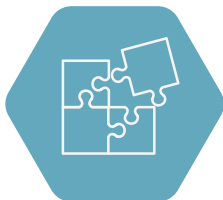
Understanding and building strong relationships with key stakeholders is critical to effectively creating a business case



Seeking diversity is important in business case partners — each has unique skills, roles, values, and other important lenses to embed into the plan



It's never too late to collect data, as the evidence has to start somewhere



Genetic counselors possess many skills to broaden and apply to business cases



Genetic counselors need to get comfortable with taking chances and making mistakes in this emerging space to advocate for our profession

# INTRODUCTION



Genetic counseling is experiencing tremendous growth and demand, a recent trend after the term was first coined in 1947.<sup>1</sup> Genetics services now extend into all health care specialties, paralleling advances in genetics and genomic medicine. Recognizing this, the National Society of Genetic Counselors (NSGC) embedded the need to document and show the unique value that genetic counselors bring to health care, by promoting service delivery and increasing access to genetic counselor services in its 2019-2021 Strategic Plan (Strategic Areas of Focus 1 and 2).<sup>2</sup> These efforts include developing business cases for hiring, utilizing, and retaining genetic counselors in diverse work settings.

We as genetic counselors have foundational, transferable skills to develop business cases, but may not discern how these skills can be utilized in this way or have experience with business cases. NSGC sought to support genetic counselors in these efforts by holding its first Business Case Summit (BCS) in June 2021, charging the Business Case Workgroup of its Access and Service Delivery (ASD) Committee to organize and host this virtual event.

**The introductory approach in this white paper intends to engage and empower genetic counselors broadly, to explore this topic in their settings.**

Genetic counselors with business case experience convened to share ideas, challenges, and learnings that are captured at a high level in this white paper. The introduction here intends to engage and empower genetic counselors broadly to explore this topic in their settings, fostering future efforts and resource development. While the intended audience is primarily United States-based, some elements apply across global regions and health systems, and business case details are ultimately unique (regardless of geography).

# WHY DEVELOP BUSINESS CASES?



Business cases are tools created and used to convince your target audience that the idea/service/product you are pitching is a good investment to solve a problem. Elements are shared across business cases, even if their construction and final formats vary. Common business case elements include: what is being offered and why, an analysis of the market (including gaps that can be filled), and the financial/resource impact of implementing the idea.

Business cases are often used to hire, utilize, and retain genetic counselors. These business cases can address challenges resulting from a rising workforce and demand for equitable access to genetic counseling services (herein assumed to be provided by genetic counselors). Many genetic counselors may not have business case experience because this work often falls on managers, administrators, or others in leadership.

**In the genetic counseling context, business cases are often used to hire, utilize, and retain genetic counselors.**

Billing and reimbursement are discussed in most genetic counseling business cases. This helps to articulate monetary value in a common model. However, challenges surround genetic counseling billing and reimbursement practices. Despite the growth and diverse roles of genetic counselors in health care, there is no standardized billing practice for genetic counseling services in the United States (U.S.). Genetic counselors in the U.S. are eligible to obtain a national provider identification (NPI) number, yet are not universally recognized as providers by payers (e.g. U.S. Centers for Medicare and Medicaid Services, CMS). When reimbursement is possible it can vary depending on insurance, state licensure, and institutional billing practices.<sup>3</sup> These and other gaps limit the ability to define and quantify our value as genetic counselors (see Table 1).

# WHY DEVELOP BUSINESS CASES?

Table 1. Example Gaps that Challenge Genetic Counseling Business Cases (adapted from Mary E. Freivogel, MS, CGC)

Overall	Related to Institution and/or Region	Related to Billing and Reimbursement	Related to Individual Practice
Awareness of genetic counseling services	CMS or other recognition of genetic counselors	Limited/no billing, including for CPT® code 96040	Independence of practice
Data (e.g. billing, revenue, genetic counseling outcomes, business cases)	Payer credentialing	Limited/no reimbursement for CPT® code 96040 (third party, CMS)	Inefficiencies in workflows, system, lack of data
Other resources to support business case development	Institutional credentialing	Limited/no contracted rate for CPT® code 96040 (third party)	Patient access to genetic counseling
	State licensure, other regulation	EHR-related issues about claims and billing	

CMS: U.S. Centers for Medicare and Medicaid Services; CPT®: Current Procedural Terminology (code 96040 is for “Medical Genetics and Genetic Counseling Services,” established in 2007)<sup>3,4</sup>; EHR: electronic health record



# WHY DEVELOP BUSINESS CASES?

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There is also a dearth of data related to genetic counseling business cases when compared to other health care professions (e.g. nurse practitioners, physician assistants). This makes engaging external specialists to offer us expertise and guidance, such as a health economist or business analyst, difficult. NSGC's membership has worked to develop resources on this topic (see Appendix) to fill some gaps. However, to date the organization has not formally collected data on business case utilization amongst its members to identify where, how, and why business cases are being used and outcomes from those efforts. The 2021 BCS provided a new avenue to share and collect insights about specific business cases that genetic counselors developed, as well as to identify gaps in knowledge, barriers, and resources to provide support for business case and billing protocol development.

## BUSINESS CASE SUMMIT BACKGROUND

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In keeping with its charges, the ASD Committee tasked its Business Case Workgroup to organize the BCS to advance NSGC's business case strategy. The BCS enabled attendees to share perspectives and best practices to inform NSGC's business case efforts, with goals and impact as outlined in Table 2. Many organizing and planning practices were new, since the BCS was the first of its kind for NSGC. In the spirit of creating a safe and open forum for participants to share freely, the BCS observed the Chatham House Rule<sup>5</sup> throughout.

# BUSINESS CASE SUMMIT BACKGROUND



Table 2. NSGC 2021 Business Case Summit Goals and Objectives

## Goals

- Provide a platform for genetic counselors to share their experiences about business case development and/or professional/facility fee billing
- Collect information and data about specific business cases that genetic counselors have developed in their work settings
- Identify gaps in knowledge, barriers, and additional tools/resources that would help genetic counselors develop business cases and/or billing processes

## Objectives

- Educate members about using business cases to advocate to their institutions and other relevant stakeholders to enable genetic counselors to practice at the top of their scope
- Provide NSGC with recommendations for tools and resources that would enhance genetic counselors' ability to implement/develop business cases and/or professional fee billing protocol

Correspondence with participants (phone and email) informed the BCS agenda, leading to four main topics:

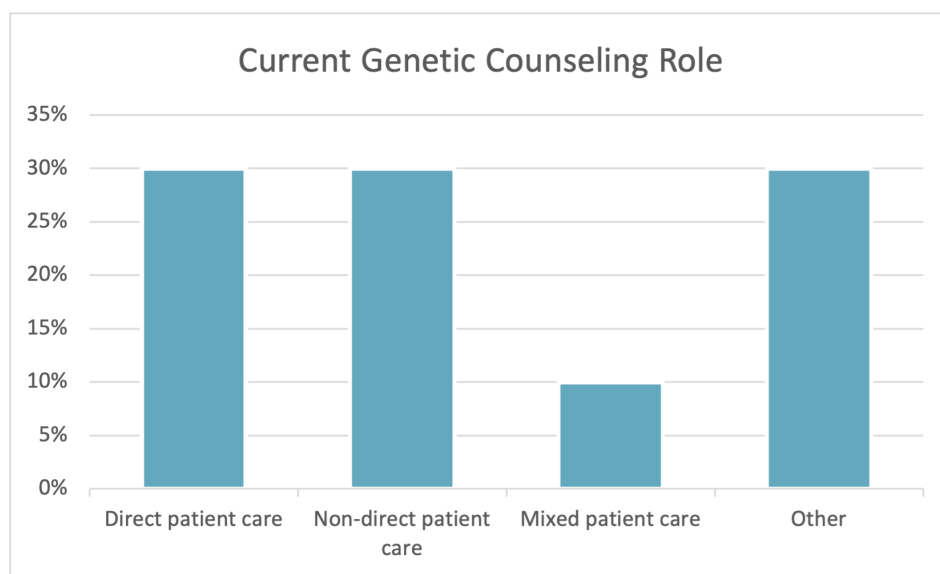
- Business case examples
- Billing and reimbursement
- Downstream metrics (e.g. revenue)
- Other metrics (e.g. patient-reported outcomes, quality measures, patient satisfaction)



# SUMMIT PARTICIPANTS

To identify BCS participants, a brief survey was emailed to the NSGC membership asking members to indicate if they: 1) had experience in business case development and/or establishing billing protocols; 2) would share the primary genetic counseling role around which the business case was developed; 3) would share their contact information for further correspondence. Of twenty-one genetic counselors asked, all accepted an invitation to participate in the BCS (see Acknowledgements for BCS participant listing). Twenty participants (95%) completed a pre-BCS survey to better understand their experience and background coming into the event. See Figure 1 for a breakdown of responses.

Figure 1. Pre-Business Case Summit Survey Responses (courtesy of Erin M. Miller, MS, CGC and Breanna Roscow, MS, CGC)



- N=20 respondents
- Average of 17.4 years of genetic counseling experience
- 5 held advanced degrees beyond Master's in genetic counseling
- 65% had direct reports at current place of employment

# SUMMIT PARTICIPANTS



Respondents were highly experienced and held leadership positions at their current or prior institutions. They represented diverse work settings (e.g. academic or public hospital, private company, diagnostic laboratory) and clinical areas of expertise. Of note, 100% of participants reported previous experience developing a genetic counseling business case, even if their attempts were not successful. Most

**Most reported that they learned about business case development while on the job, with limited formal training or support.**

reported that they learned about business case development while on the job, with limited formal training or support. Relatedly, 60% reported prior experience with billing and reimbursement for genetic counseling services, with 87.5% reporting challenges or barriers to starting billing practices.


## BUSINESS CASE SUMMIT THEMES

This white paper is an invitation for us to learn more about creating genetic counseling business cases, with high-level takeaways from the BCS as a framework. Presentations and discussions between BCS participants yielded seven themes, summarized in Figure 2. These are discussed in subsequent sections with recommended points or strategies. Recommendations are not meant to be prescriptive and may not apply to your situation. Themes intersect and need not always be followed in the order presented.

# BUSINESS CASE SUMMIT THEMES

Figure 2. Themes from the NSGC 2021 Business Case Summit





# BUILD RELATIONSHIPS TO BUILD EFFECTIVE BUSINESS CASES

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Like an effective genetic counseling practice, business cases are built on relationships, the focus of the BCS keynote address. Relationships need time and care, similar to planting seeds for growth. Genetic counseling services are often delivered in specialty departments, leaving genetic counselors siloed within a system. This makes it difficult for potential business case partners to know that you are there, what you do, or what your needs may be. Fortunately, genetic counselors often have core relationship-building and communication skills to focus toward building a business case.

**Contributing to external efforts lets you learn what others are doing, and mitigates a “self-serving” perception if a genetic counseling business case request arises later.**

Early steps in building a relationship may happen before the value of the relationship is apparent. When thinking about these early stages, “Who knows you is more important than who you know,” offered the BCS keynote speaker, a genetic counselor who has created business cases in large health systems. It requires deliberately emerging from a home department to be seen, expanding a network, learning about leadership opportunities at the institution, even helping with external projects. Contributing to external efforts lets you learn what others are doing, what their needs are, and mitigates a “self-serving” perception if a genetic counseling business case request arises later.

# BUILD RELATIONSHIPS TO BUILD EFFECTIVE BUSINESS CASES

BCS participants recognized that there may not be time for these efforts, especially if they are outside job duties. But if the current situation does not allow for relationship-building and you see a need, share that with leadership. Offer the “why,” and what the time/effort can offer. Even if an interaction does not immediately lead to gains, time is not wasted because effective relationships are not transactional. Each attempt can scatter seeds for future growth and goals that are not yet envisioned. Try to view yourself as a “team member for the system,” said the BCS keynote speaker. This is a powerful lens for genetic counseling business cases, particularly when identifying partners (see Engage a Variety of Partners for Success theme).



## Guideposts to Building Relationships for Business Cases

- Start early, often before a business case need is apparent or pressing
- Develop relationships with potential business case partners before asking for anything
- Be seen: volunteer to help other departments or company initiatives
- Always think about the next goal you may have
- Look for conscious and unconscious bias, in you and others
- Learn another group’s language and needs
- Ask others for ways to grow a network to help a business case
- Assume positive intent
- Position yourself as a collaborative team member for the system
- Gain an understanding of how it all works and how your business case could fit in

# ENGAGE A VARIETY OF PARTNERS FOR SUCCESS



Many BCS participants expressed a need to bring in individuals/groups with diverse backgrounds, expertise, and skills for the best chance to have a successful genetic counseling business case. Going it alone can actually lower a business case's chance for success. Ideally, relationships with business case partners are developed before a request is made (see Build Relationships to Build Effective Business Cases theme).

**Going it alone can actually lower a business case's chance for success.**

**Who is an advocate? Who is a decision maker? Who blocks efforts? Who are the users?**

Participants said it can take pushing out of your comfort zone to think about business cases, such as learning about billing and reimbursement. However, BCS participants said this was essential to do for a business case. You may need to find training or other ways to prepare yourself (see Hone Skills You Already Have to Make Business Cases theme).

Engage partners with different perspectives, such as finance, payers, health system administration (see below). Sometimes, someone may have a personal connection that deepens their purpose to your cause. Other times, someone may have priorities that block your own. Ask others for suggestions to avoid conscious and unconscious biases that impact your thinking. One BCS speaker, a senior client executive at a genetic counseling services and utilization/claims management company, suggested four questions to think through: Who is an advocate? Who is a decision maker? Who blocks efforts? Who are the users?

# ENGAGE A VARIETY OF PARTNERS FOR SUCCESS

BCS participants admitted that it can be hard to balance all opinions, needs, and desires. Building a business case can be framed as a guided process towards a mutual goal. Fostering relationships beforehand builds trust and comfort to ask hard questions. Meet before writing to get individuals on board with the planning and address misalignments. Convincing leadership and other key stakeholders is also an important step, as they can be your champions in the work. It is valuable to sync on many aspects with ongoing conversations (see Align on Goals, Priorities, and Timing theme).



## Suggested Genetic Counseling Business Case Partners

- Administrative (clinical, health system)
- Billing / Coding
- Business strategist
- Client services / Sales
- Clinical
- Finance / Revenue cycle / Fundraising
- Health economist
- Patient relations
- Payer (e.g. insurance)

# ALIGN ON GOALS, PRIORITIES, AND TIMING



It is frustrating to make progress on a genetic counseling business case, only to find out that an assumption about goals was a deal-breaker. You might be left wondering: How did this get missed? Weren't we after the same thing? A theme throughout the BCS was to proactively seek alignment on key issues during the business case process. Goals, priorities, and timing may shift and it can be surprising to learn about misalignments. These may even be within our own department, where we often have biases and blind spots.

Participants recommended seeking alignment early to uncover issues at a manageable stage (see Proactively Address Common Challenges theme), including:

- **Audiences:** Who is your business case targeting? Define this up-front to tailor messaging. There may be multiple audiences, with decision makers at different levels.
- **Goals:** What is everyone trying to achieve, individually and collectively? Some goals may conflict, but try to connect the dots to find alignment.
- **Priorities:** What is important to everyone? What is highly valued by one may not be for the other, and may even detract.
- **Language:** What do key terms mean? Each field has its own language shortcuts. Ensure everyone knows what key terms mean to avoid confusion.
- **Timing:** Is this the right time for a business case? Your ideal timing could be the opposite for another. Revenue cycle timing can impact business cases.
- **Growth:** Does everyone feel hiring genetic counselors is beneficial? Identify gaps in understanding growth trajectory, capacity, and downstream implications, to frame the business case's value.

**Misalignments may even be within our own department, where we often have biases and blind spots.**



# ALIGN ON GOALS, PRIORITIES, AND TIMING

Building business cases requires ongoing communication and care. Package solutions and statistics to your audiences, whenever possible.



## Suggested Questions to Gain Alignment for Business Cases

- How do all genetic counselors feel about a business case? Those in different specialties often have different motivations and pain points.
- How do billing and reimbursement fit in? Are all possible services included in current coding and billing practices? Is recouping salary the goal or is there something else?
- How does genetic testing management factor in? Are there organizational costs that could result from the incorrect/inappropriate use of genetic testing?
- How do licensure, credentialing, and cross-appointment (e.g. direct patient care and teaching and/or research work in different departments) factor in, if applicable?
- Is your institution a referral center or are there institutional partners? Could a business case have downstream referral or revenue implications, or widen health disparities?
- Do institutional/system and individual goals differ? Common goals include: downstream revenue, referral partners, cost savings (e.g. reducing time to a diagnosis), lives saved, quality of life, marketing, public opinion (e.g. “good press”).
- Is your business case solution framed correctly? This might vary by group.

# PROACTIVELY ADDRESS COMMON CHALLENGES



As mentioned in the Introduction, there are challenges to creating business cases to increase genetic counseling access and service delivery. BCS participants openly shared their difficulties. A frequent sentiment was that even with the best preparation, success is not guaranteed. As one BCS speaker, a team leader who created a new specialty genetic

**Half of pre-Summit survey respondents reported having their business case "ask" denied on the first attempt.**

counseling clinic at their institution, shared, "It can take much effort to build, little to break." Half of respondents in the pre-BCS survey reported having their business case "ask" denied on the first attempt. Many suggested proactively addressing common challenges (see Align on Goals, Priorities, and Timing theme). Determine who "owns" a problem as it arises, which may go back to the ultimate decision maker for each audience.

A business case is built on relationships, so working group changes can have a major impact. If a key leader leaves and was your champion, that can be difficult to absorb — particularly if the replacement is unsupportive of your efforts. Or maybe one of your direct colleagues blocks your business case because it would make their job harder. When conflicts arise, remind yourself that detractors are not your opponent or enemy. "Everyone is trying to make the system work," offered the BCS keynote speaker. Asking questions and growing your network (see Build Relationships to Build Effective Business Cases theme) can improve your visibility and lines of sight. As you do this, you can find mentors within your institution to help.

# PROACTIVELY ADDRESS COMMON CHALLENGES



## Common Business Case Challenges to Address

- **Detractors:** These may be internal or external. If your group has genetic counselors across specialties, some might have reason to block.
- **Misconceptions:** For example, what is often referred to as a genetic counseling workforce shortage is actually a distribution problem, as shown with cancer genetic counselors in the U.S.<sup>6</sup>
- **Billing, Pricing, Reimbursement:** Are genetic counselors billing? Should you use a professional fee, facility fee, other? What codes? What is a reimbursement rate that reflects your value (see Clearly Articulate and Ask for Your Value theme)?
- **Limited/No Data:** Genetic counseling data can be hard to find or not exist. Try to find data that connect service delivery, to billing/coding, to reimbursement. Some decision-makers want data and do not know that genetic counseling has a scanty evidence base right now (see Collect Data to Tell a Compelling Story theme).
- **Disconnectedness:** Consider and capture all service locations and delivery models (e.g. telephone, telemedicine, in-person).
- **Genetic Counselor Recognition:** Does licensure, credentialing, being in-network, having an Advanced Practice Provider designation (like nurse practitioners or physician assistants) impact data or goals?
- **Health Disparities:** Are there groups that cannot access genetic counseling? Are billing and reimbursement practices creating or widening health disparities?<sup>6</sup>
- **Thinking Long-Term:** Try to project longitudinally to build this into your story, including addressing any barriers (e.g. access, implementation).

# COLLECT DATA EARLY TO TELL A COMPELLING STORY



Data often convey the story for genetic counseling business cases. BCS participants recognized the value of data to support a business case and restated the need to learn about billing and reimbursement practices. One BCS speaker, a team leader who created an independent genetic counseling department at their institution, offered, “Data is necessary for change. Start collecting data before you think you need it.” Participants admitted that there may be no data to analyze. So, then what? Share limitations to help others understand gaps, recognizing that it’s never too late to start collecting data.

**“Data is necessary for change. Start collecting data before you think you need it.”**

Participants recommended connecting genetic counseling services to patient outcomes when possible. Try using indirect measures, such as lab work secondary to genetic counseling services. One BCS speaker, a genetic counseling

leader at a hybrid utilization management and genetic counseling service, suggested thinking beyond typical data points. Case examples and family/patient stories can offer context. If it works for your institution, consider framing the story around lives saved, patient satisfaction surveys, or improved quality of life.

Data collection and tracking tools came up throughout, listed in the Appendix. Many expressed a need for more training on data collection and analysis, during and beyond graduate training. Participants used diverse approaches with research and clinical frameworks. Some used validated instruments to measure genetic counseling quality and outcomes under a quality improvement initiative, outside of research. To make tracking manageable, some started with a pilot of patients and extrapolated to an entire patient population (as appropriate). Establishing and maintaining data collection often took ongoing collaboration with administration, finance, and other partners.

# COLLECT DATA EARLY TO TELL A COMPELLING STORY

Participants also candidly said that some genetic counselors may not want outcomes measured. The idea of having one's performance measured is unnerving if it is linked to annual reviews, raises/bonuses, and/or employment. However, decision makers need to know that genetic counseling is making a difference and outcomes are a way to show this. Understanding concerns from detractors (see Proactively Address Common Challenges theme) can mitigate unwelcome surprises with business cases.



## Things to Consider When Collecting Data for Business Cases

- What does success look like to your audience? You may be asked to benchmark, doing a comparison of key measures/metrics.
- What and where are the data points to track (see Appendix for examples)? Partners might know of resources (see Engage a Variety of Partners for Success section).
- How much time is needed to collect and maintain the data? Can data be integrated with an electronic health record (EHR) or a patient portal to build efficiency?
- Is the data collection part of a research or clinical initiative, or both?
- Do you need to capture patient-related activity (indirect patient care)? Are data limited to patients that pursue genetic testing?
- Can you access downstream revenue data? <sup>7</sup>Tracking adherence to surveillance and other recommendations <sup>8</sup>after genetic counseling may be part of this.
- Should the data include genetic counseling assistant (GCA) activities (see Limitations section)?

# CLEARLY ARTICULATE AND ASK FOR YOUR VALUE



BCS conversations raised the need to determine, convey, and ask for your value when building a genetic counseling business case. In the financial context, this arises when calculating salary, estimating impact on a patient's health outcomes, or navigating billing and reimbursement. Value can also be shown non-monetarily, such as with patient satisfaction, appropriate genetic testing usage, or adherence to recommendations. The definition of "value" is individual. Are you including all the ways that value can appear?

Participants offered honest thoughts about resistance genetic counselors may feel about asking for their value or learning about billing and reimbursement. Time was short to explore why, but many voiced that they felt discomfort and unprepared. As one BCS participant, a genetic counselor leader at a commercial diagnostic laboratory, said, "Genetic counselors

**"Genetic counselors need to get comfortable talking about money and prices, and also with making mistakes."**

need to get comfortable talking about money and prices, and also with making mistakes." Participants reminded themselves that a lack of experience does not equate to a lack of ability. Many relied on training on the job when they needed it ("just-in-time") and the expertise of others.

Genetic counselors often have limited training or experience with the financial aspects of health care. Others may worry about how their roles contribute to costs of health care and to patients. Who gets the bill? If the patient receives a big bill through a billing "pilot," who pays it? Does this worsen health disparities?<sup>6</sup> Participants identified a need for introductory business training during and after graduate training (see Next Steps section). Many recognized the difficulty to prioritize business training with no clear need for it. Engaging diverse partners helped many participants address and articulate their value (see Engage a Variety of Partners for Success theme).

# CLEARLY ARTICULATE AND ASK FOR YOUR VALUE



## Ways to Articulate Your Value Around Business Cases

- What is the value of genetic counseling in your business case? Clearly define this for you and your partners. Then, develop the story built on this value.
- Engage business strategy/finance/revenue cycle experts to help quantify value, considering for example:
  - Payer recognition: Licensure, institutional credentialing, professional/facility fees, relative value units (RVUs)
  - A market analysis: Local, regional, national, telemedicine genetic counseling services
  - Billing and reimbursement practices: Include all service delivery models (e.g. in-person, telephone, telemedicine)
- Consider if you are asking for enough monetary value to recoup your salary. Will a lower number work long-term? Can a balance be struck when considering health care costs and health disparities?
- Back up all claims with statistics and evidence, whenever possible (e.g. NSGC's Professional Status Survey, other workforce assessments)
- Look for/Ask about training you need — your institution may offer options for employees via continuing education or development

# HONE SKILLS YOU ALREADY HAVE TO MAKE BUSINESS CASES



As discussed earlier, genetic counselors have relationship-building and communication skills needed to build business cases (see Build Relationships to Build Effective Business Cases theme). These skills may be under-recognized because we are not creating a business case. Yet these skills, like building rapport and contextualizing information across audiences, are embedded in the work we already do in many settings.

**Genetic counselors need to trust and have confidence in their skills to build business cases.**

BCS participants universally offered that genetic counselors need to trust and have confidence in their skills. Yes, working on a business case might feel disorienting when those skills are being used in new ways. As one BCS speaker, a team leader who developed an independent genetic counseling

department at their institution, noted, “I didn’t realize I was building a business case.” The key is to apply the lens of creating business cases to fortify what you have. It also takes periodic reminders that a lack of experience does not equate to a lack of ability.

Participants recognized that genetic counselors will need training to fill specialized knowledge gaps, something heard throughout the BCS. This forum provided a springboard for future ideas (see Next Steps section), including learning resources and creating a network of genetic counselors with business case experience for mentorship. Participants also reiterated that the right partners were critical to helping them stretch and fill their own gaps (see Engage a Variety of Partners for Success theme). As more genetic counselors make this mental leap, the collective experience with business cases and evidence base across the field will grow.



# HONE SKILLS YOU ALREADY HAVE TO MAKE BUSINESS CASES



## Genetic Counseling Skills that Advance Business Cases

- **Actively Listening:** Picking up on overt and subtle cues to meet individual needs in a business case
- **Operating with Empathy:** Trying to inhabit someone else's situation/needs when it comes to requests, actions, questions
- **Building Trust and Rapport Across Roles:** Recognizing the diverse perspectives and contributions that shape your business case holistically
- **Asking Questions to Foster Understanding:** Regularly checking in with people to ensure everyone understands and wants the path forward
- **Tailoring Information:** Packaging your business case statistics, story, solutions to what people want and need
- **Using Shared Decision-Making:** Collectively building consensus as you move ahead
- **Advocating:** Trying to advance an overall cause or purpose for a group/individual
- **Remaining Flexible in Dynamic Spaces:** Recognizing when you need to pause to re-evaluate if you hear or anticipate changes to the plan
- **Following Up:** Prompting, managing, and completing details of the plan as appropriate

# LIMITATIONS



No perspectives outside the genetic counseling community, such as a health economist, business analyst, or finance specialist, were part of the BCS. NSGC attempted to find a health economist to be involved in this work and for many reasons (e.g. limited evidence base leading to low interest, COVID-19 pandemic) did not succeed. Participants noted that external expertise is still needed to bring objectivity, expertise, and specialized knowledge as this work progresses.

BCS participants appeared to be fairly homogeneous — for example, all were highly experienced genetic counseling leaders/managers in their institutions, and in the profession. Each developed a business case before the BCS, not typical of most genetic counselors. The BCS workgroup sought out this experience in BCS participants to maximize learnings. That said, this is a limitation that may bias assumptions, ideas, and diversity of opinions, particularly about what the average genetic counselor has the awareness of and time to do in this space.

This paper is written for a U.S.-based audience of genetic counselors, where there is great variation across regions, health systems, roles, cultures, or other factors. Despite this, recommendations and ideas presented may not apply to all global regions. Every situation needs to be explored and considered individually.

Lastly, conversations and business cases sometimes included genetic counseling assistants (GCAs). This document does not focus on the GCA role or its impact because GCAs were not represented in all genetic counseling teams. This is something to consider for future exploration.

# NEXT STEPS



NSGC wants to advance the momentum of its BCS with future thought and action, to engage the broader genetic counseling community. Concluding BCS sessions explored next steps. A flurry of brainstorming yielded many ideas and participants offered to help others (see Acknowledgements section for list). The Business Case Workgroup saved all ideas shared to inform future discussions with the ASD Committee and the NSGC Board of Directors. A new NSGC Strategic Plan developed in 2021 will inform future direction. Below are broad categories of the ideas shared:

- Create spaces for ideas, successes, challenges (e.g. more summits, local connections)
- Help genetic counselors understand why this issue is important to them, in their context
- Develop/Find/Share business case and data collection examples, billing and reimbursement resources (e.g. toolkit)
- Develop/Find training to fill knowledge gaps (e.g. with genetic counseling training programs, create or find on-the-job learning resources)
- Connect members with genetic counselors that have business/business case expertise (e.g. BCS participants, note in NSGConnect mentor program)
- Continue to find and dismantle barriers to payer recognition of genetic counselors
- Consider genetic counseling assistants and their role/impact in a business case

**NSGC wants to advance the momentum of its Business Case Summit with future thought and action, to engage the broader genetic counseling community.**

# CONCLUSION



NSGC's first Business Case Summit yielded high engagement and discussion from participants, shared throughout this introductory white paper:

- **Genetic counselors generally have knowledge gaps surrounding billing/reimbursement practices, leading to inconsistencies in the field.** Understanding and addressing these gaps locally will foster successful business cases to increase equitable access to genetic counseling services.
- **Understanding and building strong relationships helps to effectively create a business case.** Insights from relationships can frame statistics, stories, and solutions to help people “buy in” to a business case.
- **Seeking diversity in business case partners is vital — each has unique skills, roles, values, and other lenses to embed into the plan.** This builds inclusive, collective value for the plan.
- **It's never too late to collect data, as the evidence has to start somewhere.** Data around genetic counseling business practices are limited, but can grow. Ideally, try to collect data before it is needed.
- **Genetic counselors need to get comfortable with taking chances and making mistakes in this emerging space.** Ask management to get involved, as they may welcome the help. Stay open to the unexpected.
- **Genetic counselors possess many skills to broaden and apply to business cases.** The baseline is not zero, even if these skills are not called “business skills.” Success may not initially come, but with patience and persistence it can come eventually.

As more genetic counselors understand why and how business cases are developed, more may attempt this themselves. BCS participants voiced a strong desire to continue these conversations broadly in a professional call to action. When collective experience and confidence in this work increases, the evidence base will grow. This white paper sparks necessary future thought and action for genetic counselors and our health system partners to meet rising service delivery and equitable access needs for the communities we serve.

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# GLOSSARY OF TERMS

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- **Bias:** Attitudes, feelings, behaviors towards a group that may be within (conscious, explicit) or outside (unconscious, implicit) of one's awareness, positive or negative
- **Business Analyst:** Studies how a business operates and achieves its goals/outcomes by performing data analyses, often across departments
- **Coding (medical):** Pulling details from the EHR/clinical documentation and determining appropriate medical codes to create insurance claims and bills for patients
- **Credentialing (medical):** Determining a health care provider's qualifications, often by reviewing training and other documents for a health care role/organization/membership
- **Downstream Revenue (medical):** Monetary value/cost analysis of the patient care cycle after an initial consultation (e.g. office visits, procedures, inpatient/ambulatory care)
- **Facility Fee:** Fee paid to a facility (e.g. outpatient department) related to costs of maintaining physical structure, recruitment, and/or other expenses
- **Finance Specialist:** Determines how a business sells its services/products to achieve financial goals/outcomes, often across departments and with customers
- **Health Economist:** Uses training blended with health care industry and economics to analyze the health care system, informing health care policy and patient care quality
- **Professional Fee:** Fee related only to the services of a health care professional
- **Payer:** Party (e.g. entity/person that is commercial, private government) responsible for paying for services provided by a health care professional
- **Revenue Cycle (health care):** Financial process for a health care system that starts from medical coding/billing, to reimbursement/denial, to collections, to payment

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# APPENDIX



1. NSGC Genetic Counseling Literature Repository (2021, NSGC Research, Quality and Outcomes Committee)
  - NSGC Genetic Counselor Research Repository Compendia
    - Arguing the Business Case
    - Improving Patient Care: Clinical Value of Genetic Counselors
    - Increasing Access to Genetic Services and Growing the Genetic Counseling Workforce
2. Example data points to collect (as applicable)
  - Patients seen (type and number)
  - Appointment wait times and satisfaction rates
  - Direct and indirect revenue (beyond recouping salary)
  - Regional areas serviced (e.g. ZIP or postal code)
  - Health outcome measures, lives saved
  - Length of time to a genetic diagnosis
  - Cost-savings from surveillance, emergency department usage, genetic testing utilization (including waste)
3. Example tools to collect and analyze data (all as applicable)
  - Patient experience/satisfaction surveys
    - REDCap (2021, Vanderbilt University and National Institutes of Health)
    - Press Ganey (2021, Press Ganey Associates, LLC)
    - Qualtrics (2021, Qualtrics)
    - Net Promoter Score<sup>SM</sup> (2021, Bain & Company, Inc., Satmetrix Systems, Inc., Fred Reicheld)
  - Validated clinical assessment instruments
    - Genetic Counseling Outcome Scale (general; 2011, McAllister M, et al.)
    - Genomics Outcome Scale (short-form) (general; 2019, Grant PE, et al.)
    - GAD-7 (for generalized anxiety disorder; 2006, Spitzer RL, et al.)
    - PHQ-9 (for depression severity; 2001, Kroenke K, et al.)
  - Time-tracking tools
    - Clockify (2021, COING Inc.) and Toggl (2021, Toggl)
4. Example ways to define/measure health care quality
  - CMS Annual Call for Quality Measures Fact Sheet (2021, Centers for Medicare and Medicaid Services)
  - The Quadruple Aim model (2014, Bodenheimer T & Sinsky C)