The University of Arizona Genetic Counseling Graduate Program: Addressing the Gap in Clinical Genetics Services in Arizona

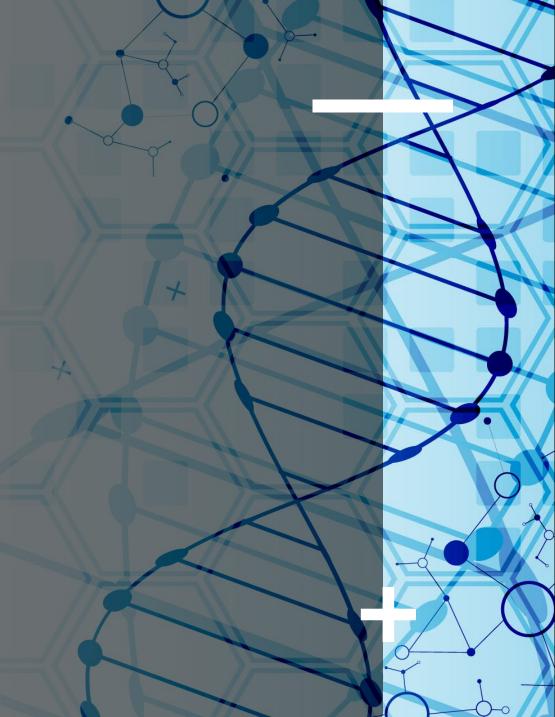
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Conflict of Interest

None to disclose.

Outline

- Who are clinical genetics providers?
- What are the barriers to clinical genetics services in the US?
- What is the state of clinical genetics services in Arizona?
- What is the University of Arizona Health Sciences and the Genetic Counseling Graduate Program doing to address these issues?

Learning Objectives

- 1. Define and discuss genetic counseling and the role of genetic counselors in clinical care.
- 2. Recognize the state of the clinical genetics workforce in Arizona.
- 3. Describe the steps that the UArizona Health Sciences and the UArizona Genetic Counseling Graduate Program are taking to address the lack of geneticstrained healthcare providers in the state.



Genetics Health Care Providers

- Clinical geneticists
- Genetic counselors
- Genetics nurses
 - "A genetics nurse is a licensed professional nurse with special education and training in genetics." International Society of Nurses in Genetics
- Other healthcare providers
 - Nutritionists
 - Physician assistants
 - Physical therapists



Who are clinical geneticists?

- "Clinical geneticists are **physicians** who care for patients in **clinical settings** and often carry out clinical or translational research related to patient care. They hold **American Board of Medical Genetics and Genomics (ABMGG) certification** in the specialty of **clinical genetics** and genomics and have broad training in the

evaluation, diagnosis, management and treatment of inherited conditions in patients across all ages from birth to adulthood."

American College of Medical Genetics





Who are genetic counselors?

- "Genetic counselors are professionals who have specialized education in genetics and counseling to provide personalized help patients may need as they make decisions about their genetic health."
- National Society of Genetic Counselors







Who are genetic counselors?

- Board certification by the American Board of Genetic Counseling (ABGC)
- Highly trained in genetics, genetic testing and counseling
- Deliver pre and post test counseling
- Work with the healthcare team to identify appropriate testing
- Work in a variety of specialized areas of medicine (prenatal, pediatrics, adult, cancer, etc)

Barriers to Accessing Clinical Genetics

01

Insufficient number of genetics providers

02

Distance to care

03

Lack of recognition among primary care providers about the need for referral to genetics clinics 04

Poor insurance coverage

05

Misconceptions about genetics services



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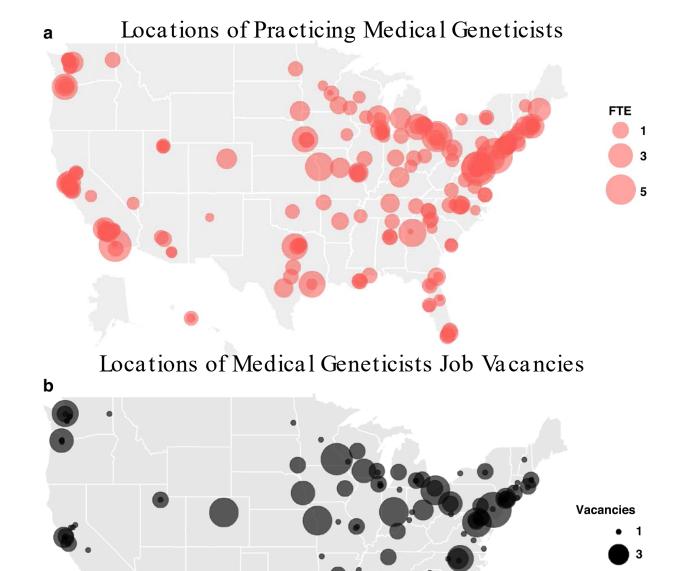
Poor insurance coverage 05

Misconception about genetics services



Lack of Clinical Medical Geneticists

- In the US, there are currently about 1,800 certified clinical medical geneticists
 (ABMGG Statistics, 2021)
- Nationwide, there are only about 0.2 practicing clinical geneticists per 100,000 people (Maiese et al., 2015)
- Unfilled clinical geneticist positions at many institutions unfilled for >3 years (Jenkins et al., 2019)
- 39% of nonemergency patients waiting >3 months for a clinical geneticist appointment (Jenkins et al., 2019)



Small Provider Stream in Clinical Genetics

NRMP Match Rates for Pediatrics-Medical Genetics

Year	Positions Offered	Positions Filled	%
2023	25	23	92%
2022	30	28	93%
2021	27	25	92%
2020	22	20	91%
2019	21	16	76%
2018	20	18	90%
2017	15	13	87%
2016	14	14	100%
2015	15	15	100%

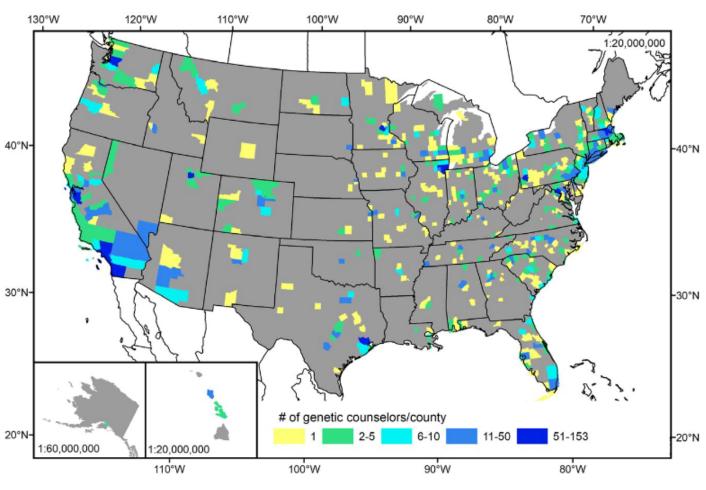
NRMP Match Rates for Medicine-Medical Genetics

Year	Positions Offered	Positions Filled	%	
2023	4	3	75%	
2022	5	3	60%	
2021	4	4	100%	
2020	4	3	75%	
2019	3	1	33%	
2018	1	1	100%	
2017	2	1	50%	
2016	1	0	0%	
2015	4	4	100%	

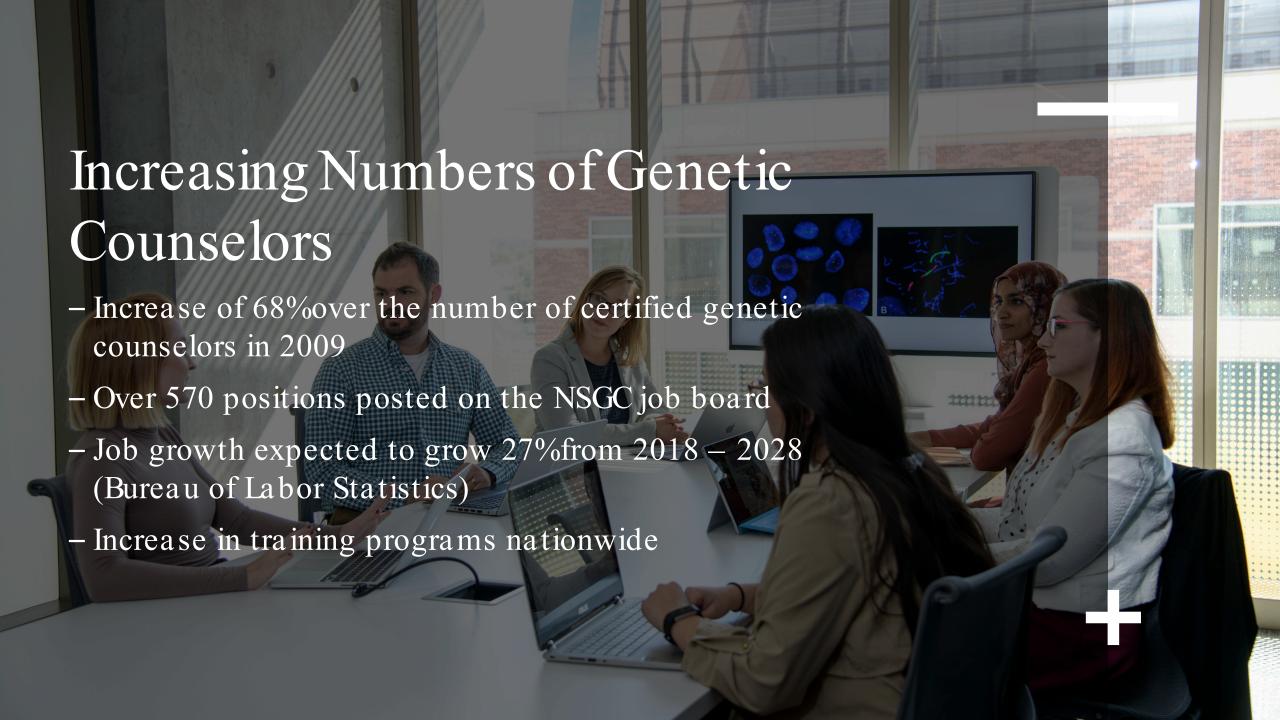


Lack of Genetic Counselors, Especially in Rural Areas

- Workforce projections estimate demand of 1 FTE clinical genetic counselor per 75,000 (Hoskovec et al., 2018)
- Nationwide 1 genetic counselor per 71,000 individuals (Triebold et al., 2020)
 - 49% of genetic counselors report working in non-direct or mixed patient care (2022 NSGC PSS)
- Only 17% of US counties has at least 1 genetic counselor (Triebold et al., 2020)



Triebold et al., 2020



Barriers to Accessing Clinical Genetics

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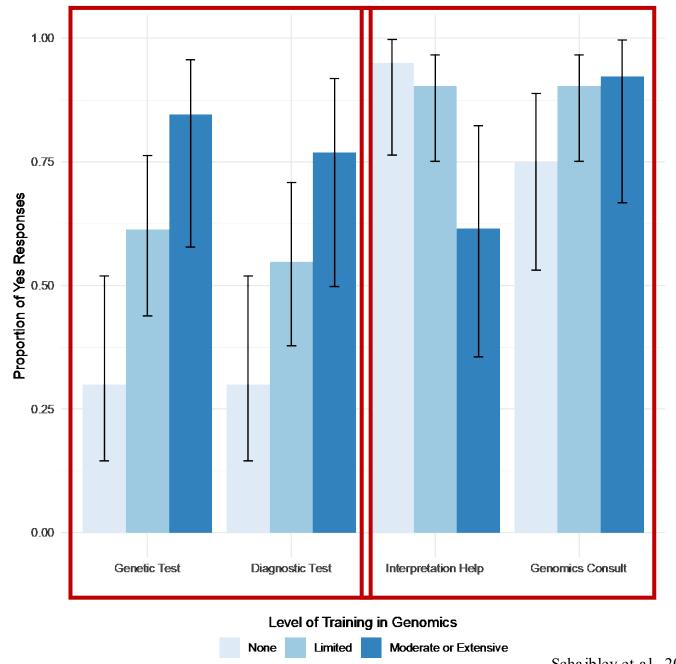


Limited Genomics Training Among Physicians Remains a Barrier to Genomics-Based Implementation of Precision Medicine

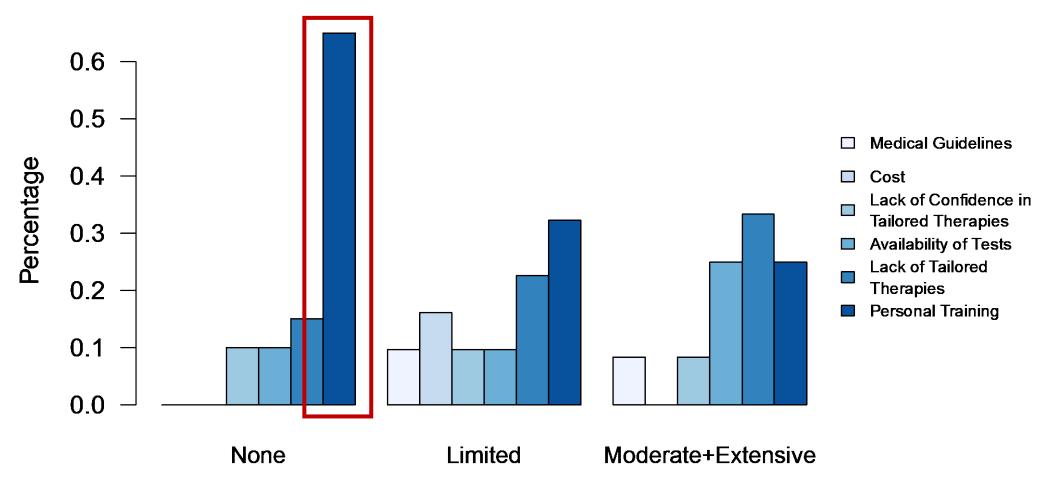
Valerie M. Schaibley¹,2,3, Irma N. Ramos¹,4, Raymond L. Woosley⁵, Steven Curry⁵, Sean Hays⁵ and Kenneth S. Ramos¹,5,7*



Level of training in genetics influences use of genetic testing in clinical settings



Lack of Personal Training in Genomics is a Barrier to Clinical Genetic Testing





Location of Clinical Geneticists and Genetic Counselors in Arizona

All clinical genetic counselors,
 medical geneticists and genetics
 nurses are located in Phoenix
 and Tucson

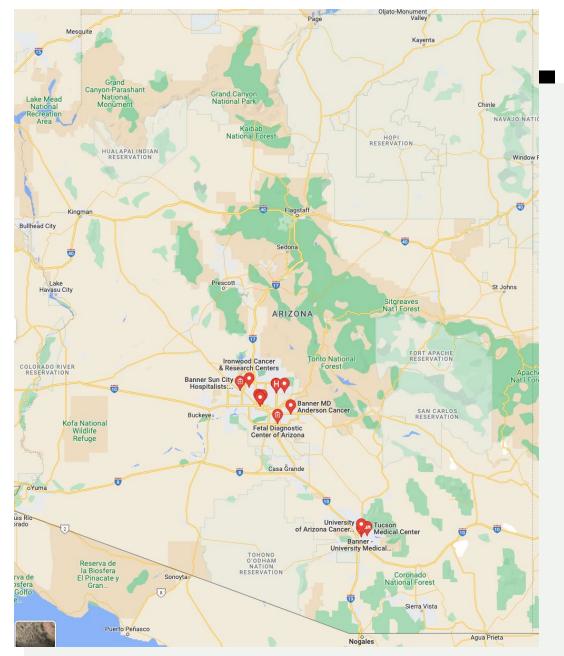
- Nogales: 66 miles

- Sierra Vista: 76 miles

- Flagstaff: 145 miles

- Yuma: 185 miles

- Page: 273 miles





Lack of Clinical Geneticists for Arizona Population

State	Population (US Census Bureau, 2020)	Clinical Geneticists (ABMGG, 2022)*	Clinical Geneticists per 100,000
Minnesota	5,706,494	30	0.53
Indiana	6,785,528	20	0.29
Arizona	7,151,502	13	0.18
Washington	7,705,281	40	0.52
Virginia	8,631,393	20	0.23

^{*}Likely overestimates of the number of practicing clinical geneticists.

Lack of **Genetic Counselors** for Arizona Population

State	Population (US Census Bureau, 2020)	Genetic Counselors* (2022 NSGC PSS)	Est. Genetic Counselor Need (Hoskovec et al., 2018)
Minnesota	5,706,494	102	76
Indiana	6,785,528	53	90
Arizona	7,151,502	25	95
Washington	7,705,281	72	102
Virginia	8,631,393	69	115

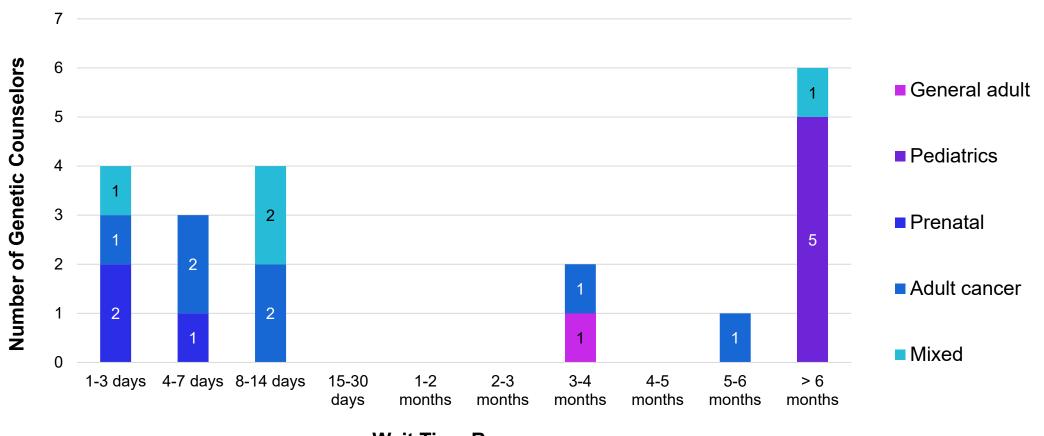
^{*}Likely overestimates of the number of clinical genetic counselors.

Insufficient Number of Genetic Counselors for Arizona Population

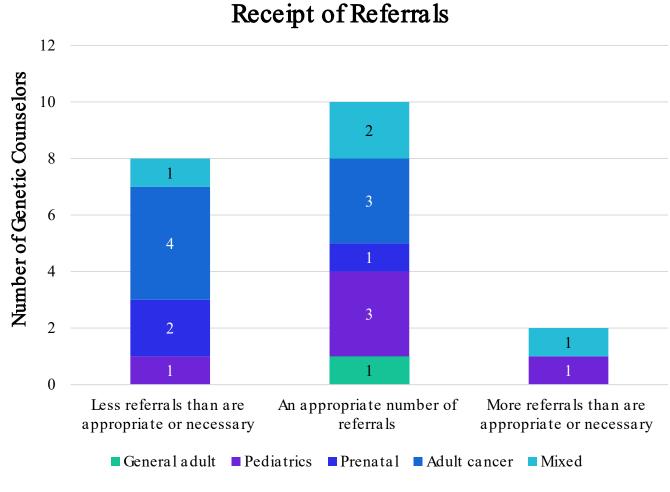
- Data from a recent workforce assessment survey from the UAGCGP:
 - Survey to GCs in Arizona in the Arizona Genetics Alliance asking about patient loads,
 wait times, capacity, etc.
 - 28 GCs in Arizona and only 20 working in direct patient care (Engle et al., in preparation)
 - Deficit of 75 clinical GCs in Arizona
 - 75% of clinical GCs in AZ report patient loads meeting or exceeding monthly capacity (Engle et al., in preparation)



Long Wait Times for Genetic Counseling in Arizona



Lack of Referrals to Genetic Counselors in Arizona







Case Example 1 (Arizona)

- A primary care provider was seeing a patient with a family history of breast cancer. The patient's sister had a positive genetic test for one of the BRCA genes, which increases their risk of breast and ovarian cancer. The provider misinterpreted the test result, thinking that the patient had the BRCA mutation. The provider then recommended preventative survey (bilateral mastectomy and oophorectomy) for this patient.
- After consulting with a genetic counselor, the appropriate test was ordered for the patient. The **test result was negative for the patient** (they did not have a mutation in BRCA1/2).
- No prophylactic surgery was necessary in this patient.

'Damaged for the rest of my life': Woman says surgeons mistakenly removed her breasts and uterus



Elisha Cooke-Moore (Elisha Cooke-Moore)

- Primary care provider ordered genetic testing for Elisha Cooke-Moore based on family history of cancer
- Test result was negative, but was misinterpreted by a nurse practitioner as Lynch Syndrome
 - Increased risk for colon and uterine cancer
- Specialist providers continued to misinterpret, and patient had hysterectomy and double mastectomy
- Patient themselves found out their test result was negative and no surgery was required



WHAT CAN WE DO?

OFFER GENETICS TRAINING IN ARIZONA

- Train genetic counselors
- Genetics certificate for HCPs

HIRE GENETICS PROVIDERS IN ARIZONA

- Genetic counselors
- Medical geneticists

COMMUNITY ENGAGEMENT

- Middle, high school and community college students
- Local clinics and community

WORK WITH CLINICS

- Demonstrate value of genetics
- Share business cases
- Provide model for hiring and reimbursement
- Reminder of the desperate need for genetics

STATE LICENSURE

- Help with reimbursement
- Distinguishes who can perform genetic services
- Easier to provide tele-health services

University of Arizona Genetic Counseling Graduate Program

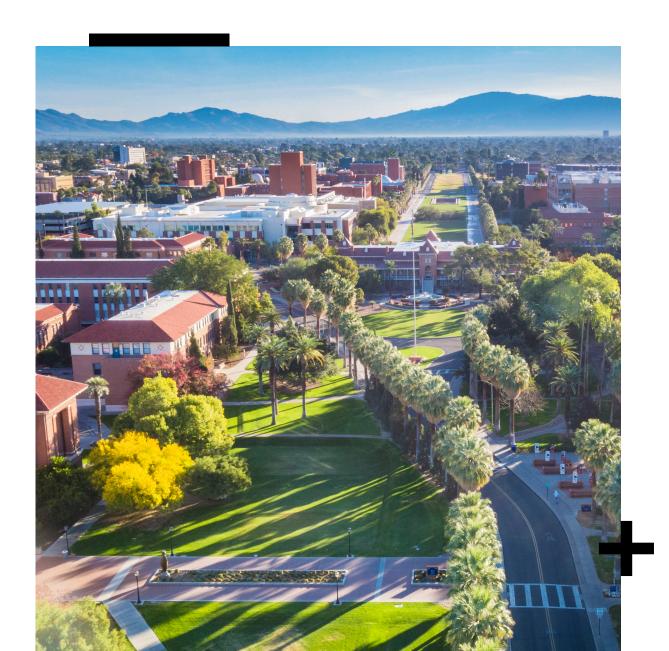
- MS degree program in genetic counseling
- Two-year program
- Combines coursework, fieldwork and research experience
- Opened in 2019
- Graduated three cohorts
- 33% of graduates currently working in AZ



Clinical Genetics Certificate Program

- New graduate certificate program being developed through University of Arizona Health Sciences
- Targeted to non-genetics specialist clinicians
 - Primary care physicians
 - General internal medicine
 - Family medicine
 - OBGYNs
- Customizable tracks focused on cancer, adult and prenatal genetics
- Planned launch: Fall 2025





Summary

- Arizona is particularly underserved for clinical genetics providers, despite a population of >7 million people
- Clinical genetics services are localized to major metropolitan areas nationwide, including in Arizona
- Increased training of specialty providers
 (geneticists and genetic counselors), offering new
 training programs for PCPs and community
 engagement can help expand access to clinical
 genetics

Thank you!

- Dee Quinn, MS, CGC
- Chris Stallman, MS,MLS, CGC
- Kathy Ben
- Lauren Maynard, MS, CGC
- Elizabeth Chavez, MS, CGC
- GCGP Students







Laura Engle, MS, GC UAGCGP Class of 2023





EXTRA SLIDES



Lack of Confidence Among Primary Care Providers

Role	Part of current practice (yes)		Level of confidence with task (high = 4 or 5 on Likert scale)	
	N	%	N	%
Eliciting information about genetic conditions as part of a family or medical history	263/282	93.3	122/277	44.0
Identifying individuals with a genetic condition	246/275	89.5	59/277	21.3
 Deciding who should be offered referral for genetic counseling or testing based on personal or family health history 	256/273	93.8	89/278	32.0
4. Knowing where to refer for genetic counseling/genetic assessment	249/271	91.9	151/273	55.3
5. Providing support to patients coping with a genetic test result	227/274	82.8	82/273	30.0
6. Evaluating the clinical usefulness of a genetic test	144/271	53.1	40/256	15.6
Discussing the benefits, risks, and limitations of genetic testing with patients	180/273	65.9	43/265	16.2
8. Describing what to expect at a genetic counseling session	169/273	61.9	57/265	21.5
9. Obtaining credible, current information about genetics	134/259	51.7	25/235	10.6
10. Providing education about genetic conditions to patients	184/272	67.6	45/265	17.0
 Discussing genetic variation in drug response with patients (e.g. pharmacogenetics) 	74/264	28.0	10/224	4.5
 Discussing the risks, benefits and limitations of "Direct-to-Consumer" genomic testing with patients 	44/263	16.7	7/213	3.3
 Discussing the interpretation of "Direct-to-Consumer" genomic test results with patients 	37/263	14.1	4/212	1.9
14. Discussing the interpretation of whole genome sequencing with patients	20/262	7.6	4/208	1.9

Do genetics providers generate revenue?

Check for updates

BUSINESS OF ONCOLOGY ReCAP

Downstream Revenue Generated by a Cancer Genetic Counselor

Caitlin B. Mauer, MA, MS, CGC¹; Brian D. Reys, MS, CGC¹; Reece E. Hall, BBA²; Connor L. Campbell, BBA³; and Sara M. Pirzadeh-Miller, MS, CGC¹

"One full-time [cancer] GC would generate \$1.49-1.86 million USD in revenue per year"

Kym M. Boycott, MD, PhD[™]

After diagnosis, "annual mean total costs for the genetic disease cohort were significantly higher than all other cohorts" (asthma, diabetes, general population).

Engagement with Local Communities

- UAGCGP student outreach project
 - 2nd year students work with area high schools and community colleges to teach students about clinical genetics and genetic counseling
- Current student capstone project
 - Very few genetic counselors from native populations nationwide
 - Goal: Engage with students from local Tucson schools to increase awareness of genetic counseling among indigenous students



Juliana Williams
UAGCGP Class of 2024

