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

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University of Arizona Genetic Counseling Graduate Program
Assistant Professor, Cellular and Molecular Medicine
University of Arizona Health Sciences
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 genetics-trained 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

https://www.acmg.net/ACMG/Education/Student/Careers_in_Medical_Genetics.aspx
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
Barriers to Accessing Clinical Genetics

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Maiese et al., 2019
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

<table>
<thead>
<tr>
<th>Year</th>
<th>Positions Offered</th>
<th>Positions Filled</th>
<th>%</th>
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<tbody>
<tr>
<td>2023</td>
<td>25</td>
<td>23</td>
<td>92%</td>
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<td>30</td>
<td>28</td>
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</tr>
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<td>2021</td>
<td>27</td>
<td>25</td>
<td>92%</td>
</tr>
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<td>2020</td>
<td>22</td>
<td>20</td>
<td>91%</td>
</tr>
<tr>
<td>2019</td>
<td>21</td>
<td>16</td>
<td>76%</td>
</tr>
<tr>
<td>2018</td>
<td>20</td>
<td>18</td>
<td>90%</td>
</tr>
<tr>
<td>2017</td>
<td>15</td>
<td>13</td>
<td>87%</td>
</tr>
<tr>
<td>2016</td>
<td>14</td>
<td>14</td>
<td>100%</td>
</tr>
<tr>
<td>2015</td>
<td>15</td>
<td>15</td>
<td>100%</td>
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</table>

 NRMP Match Rates for Pediatrics-Medical Genetics

<table>
<thead>
<tr>
<th>Year</th>
<th>Positions Offered</th>
<th>Positions Filled</th>
<th>%</th>
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<tbody>
<tr>
<td>2023</td>
<td>4</td>
<td>3</td>
<td>75%</td>
</tr>
<tr>
<td>2022</td>
<td>5</td>
<td>3</td>
<td>60%</td>
</tr>
<tr>
<td>2021</td>
<td>4</td>
<td>4</td>
<td>100%</td>
</tr>
<tr>
<td>2020</td>
<td>4</td>
<td>3</td>
<td>75%</td>
</tr>
<tr>
<td>2019</td>
<td>3</td>
<td>1</td>
<td>33%</td>
</tr>
<tr>
<td>2018</td>
<td>1</td>
<td>1</td>
<td>100%</td>
</tr>
<tr>
<td>2017</td>
<td>2</td>
<td>1</td>
<td>50%</td>
</tr>
<tr>
<td>2016</td>
<td>1</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>2015</td>
<td>4</td>
<td>4</td>
<td>100%</td>
</tr>
</tbody>
</table>

 NRMP Match Rates for Medicine-Medical Genetics

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)
Increasing Numbers of Genetic Counselors

- Increase of 68% over the number of certified genetic counselors in 2009
- Over 570 positions posted on the NSGC job board
- Job growth expected to grow 27% from 2018 – 2028 (Bureau of Labor Statistics)
- Increase in training programs nationwide
Barriers to Accessing Clinical Genetics

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04 Poor insurance coverage
05 Misconceptions about genetics services

Maiese et al., 2019
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 Curry⁶, Sean Hays⁶ and Kenneth S. Ramos¹,⁵,⁷*
Level of training in genetics influences use of genetic testing in clinical settings.

Schaibley et al., 2021
Lack of Personal Training in Genomics is a Barrier to Clinical Genetic Testing
What is the state of clinical genetics in Arizona?
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

Data from ABGC Database
### Lack of Clinical Geneticists for Arizona Population

<table>
<thead>
<tr>
<th>State</th>
<th>Population (US Census Bureau, 2020)</th>
<th>Clinical Geneticists (ABMGG, 2022)*</th>
<th>Clinical Geneticists per 100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minnesota</td>
<td>5,706,494</td>
<td>30</td>
<td>0.53</td>
</tr>
<tr>
<td>Indiana</td>
<td>6,785,528</td>
<td>20</td>
<td>0.29</td>
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<td>Arizona</td>
<td>7,151,502</td>
<td>13</td>
<td>0.18</td>
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<td>Washington</td>
<td>7,705,281</td>
<td>40</td>
<td>0.52</td>
</tr>
<tr>
<td>Virginia</td>
<td>8,631,393</td>
<td>20</td>
<td>0.23</td>
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*Likely overestimates of the number of practicing clinical geneticists.
# Lack of Genetic Counselors for Arizona Population

<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Minnesota</td>
<td>5,706,494</td>
<td>102</td>
<td>76</td>
</tr>
<tr>
<td>Indiana</td>
<td>6,785,528</td>
<td>53</td>
<td>90</td>
</tr>
<tr>
<td>Arizona</td>
<td>7,151,502</td>
<td>25</td>
<td>95</td>
</tr>
<tr>
<td>Washington</td>
<td>7,705,281</td>
<td>72</td>
<td>102</td>
</tr>
<tr>
<td>Virginia</td>
<td>8,631,393</td>
<td>69</td>
<td>115</td>
</tr>
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</table>

*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

<table>
<thead>
<tr>
<th>Wait Time Range</th>
<th>General adult</th>
<th>Pediatrics</th>
<th>Prenatal</th>
<th>Prenatal</th>
<th>Prenatal</th>
<th>Prenatal</th>
<th>Adult cancer</th>
<th>Mixed</th>
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</thead>
<tbody>
<tr>
<td>1-3 days</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4-7 days</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8-14 days</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15-30 days</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2 months</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-3 months</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>3-4 months</td>
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<td></td>
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<tr>
<td>4-5 months</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-6 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>&gt; 6 months</td>
<td>5</td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Engle et al., In Preparation
Lack of Referrals to Genetic Counselors in Arizona

Receipt of Referrals

- Less referrals than are appropriate or necessary: 1 General adult, 1 Pediatrics, 2 Prenatal
- An appropriate number of referrals: 3 General adult, 4 Pediatrics, 2 Prenatal, 1 Adult cancer
- More referrals than are appropriate or necessary: 1 General adult, 1 Pediatrics, 1 Prenatal

Engle et al., In Preparation
Lack of Access to Clinical Genetics Increases the Risk of Inappropriate Testing and Follow-Up
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.
Case Example 2

- 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

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

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
Scholarship Programs

- Financial cost of graduate school is a significant barrier to students, especially from underrepresented backgrounds
- UAGCGP looking to
  - Grow existing scholarship programs
  - Develop new scholarship programs
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
## Lack of Confidence Among Primary Care Providers

<table>
<thead>
<tr>
<th>Role</th>
<th>Part of current practice (yes)</th>
<th>Level of confidence with task (high = 4 or 5 on Likert scale)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>1. Eliciting information about genetic conditions as part of a family or medical history</td>
<td>263/282</td>
<td>93.3</td>
</tr>
<tr>
<td>2. Identifying individuals with a genetic condition</td>
<td>246/275</td>
<td>99.5</td>
</tr>
<tr>
<td>3. Deciding who should be offered referral for genetic counseling or testing based on personal or family health history</td>
<td>256/273</td>
<td>93.8</td>
</tr>
<tr>
<td>4. Knowing where to refer for genetic counseling/genetic assessment</td>
<td>249/271</td>
<td>91.9</td>
</tr>
<tr>
<td>5. Providing support to patients coping with a genetic test result</td>
<td>227/274</td>
<td>82.8</td>
</tr>
<tr>
<td>6. Evaluating the clinical usefulness of a genetic test</td>
<td>144/271</td>
<td>53.1</td>
</tr>
<tr>
<td>7. Discussing the benefits, risks, and limitations of genetic testing with patients</td>
<td>180/273</td>
<td>66.9</td>
</tr>
<tr>
<td>8. Describing what to expect at a genetic counseling session</td>
<td>169/273</td>
<td>61.9</td>
</tr>
<tr>
<td>9. Obtaining credible, current information about genetics</td>
<td>134/259</td>
<td>51.7</td>
</tr>
<tr>
<td>10. Providing education about genetic conditions to patients</td>
<td>184/272</td>
<td>67.6</td>
</tr>
<tr>
<td>11. Discussing genetic variation in drug response with patients (e.g., pharmacogenetics)</td>
<td>74/264</td>
<td>28.0</td>
</tr>
<tr>
<td>12. Discussing the risks, benefits and limitations of &quot;Direct-to-Consumer&quot; genomic testing with patients</td>
<td>44/263</td>
<td>16.7</td>
</tr>
<tr>
<td>13. Discussing the interpretation of &quot;Direct-to-Consumer&quot; genomic test results with patients</td>
<td>37/263</td>
<td>14.1</td>
</tr>
<tr>
<td>14. Discussing the interpretation of whole genome sequencing with patients</td>
<td>20/262</td>
<td>7.6</td>
</tr>
</tbody>
</table>
Do genetics providers generate revenue?

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

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

Kym M. Boycott, MD, PhD*
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