

Public Health Genetic Counselors: Activities, Skills, and Sources of Learning

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Abstract Specialization within genetic counseling is apparent, with 29 primary specialties listed in the National Society of Genetic Counselors' 2012 Professional Status Survey (PSS). PSS results show a steady proportion of genetic counselors primarily involved in public health, yet do not identify all those performing public health activities. Little is known about the skills needed to perform activities outside of “traditional” genetic counselor roles and the expertise needed to execute those skills. This study aimed to identify genetic counselors engaging in public health activities, the skills used, and the most influential sources of learning for those skills. Participants ($N=155$) reported involvement in several public health categories: (a) Education of Public and/or Health Care Providers ($n=80$, 52 %), (b) Population-Based Screening Programs ($n=70$, 45 %), (c) Lobbying/Public Policy ($n=62$, 40 %), (d) Public Health Related Research ($n=47$, 30 %), and (e) State Chronic Disease Programs ($n=12$, 8 %). Regardless of category, “on the job” was the most common primary source of learning. Genetic counseling training program was the most common secondary source of learning. Results

indicate that the number of genetic counselors performing public health activities is likely higher than PSS reports, and that those who may not consider themselves “public health genetic counselors” do participate in public health activities. Genetic counselors learn a diverse skill set in their training programs; some skills are directly applicable to public health genetics, while other public health skills require additional training and/or knowledge.

Keywords Public health genetics · Public health activities · Public health skills · Genetic counseling · Sources of learning

Introduction

Public health genomics has been defined as a multidisciplinary field concerned with “the process of selecting, storing, collating, analyzing, integrating and disseminating information both within and across disciplines for the benefit of population health” (Burke et al. 2006, p.453). As early as 1997, the Centers for Disease Control and Prevention (CDC) had developed a framework for applying public health functions when evaluating the relevance of gene discoveries to disease prevention and health promotion (CDC 1997). The public health functions included: (1) public health assessment in genetics (surveillance and epidemiology); (2) evaluation of genetic testing; (3) development, implementation, and evaluation of population interventions; and (4) communication and information dissemination (CDC 1997). Recent publications have echoed these public health functions and their potential applications in regards to genomics (Khoury and Bowen 2014). In broad terms, assessment, assurance, intervention, policy development, and communication are public health functions. In more specific terms, these functions can play out in a variety of activities and skills employed by professionals such as genetic counselors.

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Specialization within genetic counseling is becoming more prominent. In particular, more genetic counselors have public health job responsibilities and participate in public health activities. The National Society of Genetic Counselors (NSGC) is an international genetic counseling organization with more than 2,700 members (NSGC 2012a). Members include genetic counselors, genetic counseling students, physicians, nurses, and others interested in genetic counseling. The NSGC's Professional Status Survey (PSS) is a biennial survey of genetic counselors to learn about employment, specialties, professional activities, and salaries. In preparation for the current study, results from five PSSs administered between 2004 and 2012 were reviewed. Membership response rates ranged from 44 % (2012) to 71.1 % (2008), with a mean sample size of 1,257; full members of the NSGC were surveyed from 2004–2010, while NSGC members and ABGC Diplomates were surveyed in 2012 (NSGC 2004, 2006, 2008, 2010, 2012a, b).

Results of the PSS review show that between 2004 and 2012, the number of reported specialties in which genetic counselors worked increased by 17, with 29 different primary specialties listed in the 2012 PSS (NSGC 2012b). Participation in the public health specialty appears to be consistent over the last decade. However, changes in the PSS over the years makes direct comparison difficult, as the “specialty area” question was asked in different ways and with different response options, depending on the year. In 2004, 7 % of respondents reported having a public health specialty area (NSGC 2004), compared to 6 % of respondents in 2006 (NSGC 2006). In 2008, the PSS separated clinical from non-clinical genetic counselors and asked respondents to only choose a specialty area in which they spent at least 50 % of their time (NSGC 2008). Seven percent of non-clinical respondents in both 2008 and 2010 reported a public health specialty area (NSGC 2008, 2010).

In 2012, the PSS further broke down specialty roles, providing such options as “public policy,” “population-based/biobanking,” “newborn screening,” and “ethical legal social issues,” some of which were previously grouped together (NSGC 2012b). Genetic counselors who chose “public health” as a specialty area on a past PSS may have chosen one of these new options in 2012, thus reducing the number of “public health” respondents in 2012. So, while a direct comparison between PSSs is not possible, the results do indicate a steady proportion of genetic counselors in the work force who are involved in public health.

Perhaps more interesting than the number of genetic counselors who work primarily in public health, however, is the number of genetic counselors who participate in public health activities. Given that genetic counselors' day-to-day activities and job descriptions can be far-ranging, it is likely that many genetic counselors who do not consider themselves to specialize in public health do, however, participate in public health

activities. While genetic counseling provided to one patient is probably best considered “genetics health care,” activities that affect a population (such as coordination of a newborn screening program, lobbying legislators for passage of genetics legislation, or providing community genetics education) could be considered “public health activities.” Additionally, genetic counselors could participate in activities that they may not realize to be public health-related. For instance, many genetic counselors work with population screening programs or provide genetics education for healthcare professionals and the public.

Little is known about the skills that genetic counselors need to perform activities outside of traditional clinical roles, and the expertise needed to execute those skills. Results of the first formal survey of public health genetic counselors, recruited from the NSGC's Public Health Special Interest Group (SIG) and published in 2010, suggested that while public health genetic counselors were once primarily found in state public health departments, they are now employed in several arenas, including University Medical Centers, University/Non-Medical Centers, Private Hospital/Medical Facilities and Diagnostic Laboratories (Powell et al. 2010). Additionally, 82 % of respondents reported learning the necessary skills for their public health position outside of their graduate training program (Powell et al. 2010). Public health genomics/genetics initiatives, such as the CDC's Family History Public Health Initiative (CDC 2002) and Evaluation of Genomic Applications in Practice and Prevention (EGAPP) (CDC 2004), suggest that the need for genetic counselors participating in public health activities may increase. Genetic counselors are trained in the collection of family history and are familiar with genetic testing techniques and results interpretation, skills that lend themselves to initiatives such as those, above.

The Powell et al. (2010) study provided a snapshot of the public health activities in which the NSGC's Public Health SIG (PH SIG) members participated. The PH SIG is a self-selected group consisting of NSGC members with a particular interest in public health and/or self-identification as a public health genetic counselor. As such, that survey did not assess the public health participation of the larger professional membership. The goals of the current study were to identify the number of genetic counselors engaging in public health activities, the skills used to participate in these activities, and the sources of learning for those skills.

Methods

Participants

Genetic counselors on the NSGC discussion forum and NSGC PH SIG discussion forum were recruited to participate

(estimated NSGC membership with discussion forum access $N=800$). Individuals who had graduated from an accredited genetic counseling training program and worked within the United States or Canada were eligible.

Instrumentation

A novel, 58 question survey, informed by previous published surveys (Estabrooks et al. 2003; Powell et al. 2010) and the experience of two of the authors (KPP and KM), was created by the investigators. The survey consisted of three sections: 1) Eligibility, 2) Public Health Activities and Skills, and 3) Demographics. The public health activities and skills were grouped into five categories: (1) Population-Based Screening Programs, (2) Education of Public and/or Health Care Providers, (3) Lobbying/Public Policy, (4) Public Health Related Research, and (5) State Chronic Disease Programs. There were 25 yes/no questions, 26 multiple choice questions, and seven demographic questions.

A skip pattern ensured that participants only responded to questions relevant to them. The survey asked an initial qualifying question for each of the five categories, above. The qualifying question for each category specified that the activities took place and the skills were used within a public health context. Unless their involvement was self-identified as related to public health, participants did not progress from the initial qualifying question to identify specific activities or skills within a category. This was done to reduce the number of respondents who would answer questions about activities, skills, and sources of learning outside the context of public health programs/initiatives. For example, the qualifying question for the "Population-Based Screening Program" category specifically asked participants about activities "other than counseling patients about screening results." This was to separate genetic counselors providing clinical care (e.g., counseling one family about a positive newborn screening result in a metabolic clinic) from genetic counselors participating in a public health activity (e.g., a genetic counselor in a state newborn screening program reporting out abnormal results to multiple physicians and/or families).

Questions about sources of learning asked participants to identify the most influential source of learning a skill. This was not exclusionary (i.e., the "only" source of learning a skill) and thus results do not rule out more than one source of learning for each skill, but rather identify the primary source.

The demographic questions were drawn, with permission, from the 2010 NSGC PSS in order to compare results. The survey was reviewed by a survey design expert at the University of North Carolina at Greensboro and piloted with three genetic counselors familiar with public health genetics to assess content validity. Wording and formatting changes were made and the survey was re-submitted to the pilot participants to ensure face validity.

The survey and methodology was approved by The University of North Carolina at Greensboro Institutional Review Board.

Procedures

An email invitation was sent to the NSGC general member and PH SIG discussion fora. The invitation stated "The purpose of this survey is to learn about the number of genetic counselors engaging in specific public health activities and what skills they are using. It is important to learn about the activities and skills of genetic counselors to be able to delineate the skill set of the profession." It also included a description of the project, eligibility criteria, instructions, and a link to an anonymous online survey. Participants could enter their names for a chance to win a \$100 Amazon.com gift card after completing the survey. A reminder was sent two weeks after the original post. Data collection occurred for one month between January and February, 2011.

Data Analysis

All respondent data were de-identified and assigned individual unique identifiers. The data were entered into MS Excel[®] and secured with a password. IBM SPSS Statistics 20[®] software was used for statistical analysis and reporting. Descriptive statistics and frequencies were used to characterize respondents' demographic characteristics. Bivariate associations between demographic groups (i.e., years of practice as a genetic counselor, education, employment setting, proportion of hours spent on public health activities) were calculated using cross-tabulations and analyzed using a chi-square test. Statistical significance for all analyses was based on the conventional alpha level of significance at $p < 0.05$.

Results

Respondent Characteristics

The final sample included 155 respondents (estimated response rate=19 %). Forty-three individuals started the survey but did not complete it in its entirety; those participants were not included in the analysis. The majority of respondents were female (94.8 %, $n=147$), Caucasian (94.2 %, $n=146$), and had been in practice for an average of 7.81 years ($SD=8.23$). The top three workplace settings included University medical center (40 %, $n=62$), public hospital/medical facility (16.8 %, $n=26$) and private hospital/medical facility (14.8 %, $n=23$). Demographic results were compared to the NSGC's 2010 PSS results (Table 1). The 2010 PSS surveyed full members of the NSGC while the 2012 PSS surveyed full members of NSGC

Table 1 Comparison of Participant Demographics to NSGC 2010 PSS

	Demographic Information	This Study	2010 NSGC PSS
	Completed Surveys	155/2,978 (3.9 %)	1,142/2,316 (49 %)
	Gender		
	Female	147 (94.8 %)	1,085 (95 %)
	Male	8 (5.2 %)	54 (5 %)
	Ethnicity		
	White/Caucasian	146 (94.2 %)	1,060 (92 %)
	Other ^a	9 (5.8 %)	87 (7.6 %)
	Years as a Practicing GC		
	0–4 years	74 (47.7 %)	357 (51.1 %) ^b
	5–9 years	35 (22 %)	201 (28.8 %) ^b
	10–14 years	18 (11.3 %)	85 (12.2 %) ^b
	15–19 years	7 (4.4 %)	32 (4.6 %) ^b
	20+ years	21 (13.2 %)	24 (3.4 %) ^{b, *}
	Primary Employment Setting		
	University Medical Center	62 (40 %)	352 (33 %)
	Public Hospital/Medical Facility	26 (16.8 %)	151 (14 %)
	Private Hospital/Medical Facility	23 (14.8 %)	207 (19 %)
	Diagnostic Laboratory	9 (5.8 %)	96 (9 %)
	Physician's Private Practice	7 (4.5 %)	55 (5 %)
	Other**	22 (14.2 %)	210 (20 %)

^a includes Asian and Black/African American

^b $n=699$

* statistically significant ($p=0.000$)

** includes office in a government agency/health care center, HMO, bioinformatics company/health advocacy, internet/website company, research/biotech company, University/non-medical school

plus ABGC Diplomates. The current survey did not utilize the ABGC email-blast to recruit ABGC Diplomates. Study eligibility required graduation from an accredited genetic counseling training program. The 2010 PSS is therefore a better comparison for this study group. Significantly more study participants had worked for greater than 20 years, compared to 2010 PSS respondents ($p=0.000$) (Table 1).

Less than 20 % of respondents (18.7 %, $n=29$) reported being in practice for a year or less. More than three fourths (81.9 %, $n=127$) had one advanced degree, a master's degree in genetic counseling. The remainder (18.1 %, $n=28$) had one or more additional advanced degrees, including six who reported having a master's degree in public health. Less than one fifth of participants (15.5 %, $n=24$) reported spending almost half of their full time effort performing public health activities assessed in this survey.

Public Health Categories

The survey tool grouped the public health activities into five main categories, each representing a professional area in which public health activities occur. Participants were first asked a qualifying question to determine if they participated in the category within a public health context. The top three categories reported included: (a) Education of Public and/or Health Care Providers ($n=80$, 52 %), (b) Population-Based Screening Programs ($n=70$, 45 %), and (c) Lobbying/Public

Policy ($n=62$, 40 %). The other two categories reported were: (a) Public Health Related Research ($n=47$, 30 %), and (b) State Chronic Disease Programs ($n=12$, 8 %). If a participant did participate in a category within a public health context, they were then asked to identify public health activities they performed, the skill(s) these activities required, and their most influential source of learning for those skill (s). If a participant did not participate in a category within a public health context (based on their answer to the qualifying question) they skipped to the next category.

Participants reported the percent of their full time effort estimated to perform the public health activities identified in the survey. Participants who spent up to 40 % of work hours performing public health activities ($n=131$) most commonly reported job responsibilities in population-based screening programs and education of the public and/or health care providers (Table 2). More than twice as many public health activities were reported ($n=387$) by participants spending 0–40 % of their time on public health activities, compared to public health activities reported ($n=154$) by participants spending 41–100 % of their time on public health activities. However, the total number of participants spending 41–100 % of their time on public health activities was only 24, compared to 131 participants who spent 0–40 % of their time on public health activities.

The primary and secondary most influential sources of learning were determined for each skill within the public health categories. Regardless of category, “on the job” was

Table 2 Percent of Time Spent Performing Public Health Activities by Category

Percent of time spent on PH activities	Category	Number of responses*	Proportion of Total Participants (%)
0–40 % (<i>n</i> =131)	Screening	122	78.7 %
	Education	112	72.3 %
	Public policy	85	54.8 %
	Research	58	37.4 %
	Chronic Disease	10	6.5 %
	Total	387	n/a
41–100 % (<i>n</i> =24)	Research	41	26.5 %
	Education	41	26.5 %
	Screening	35	22.6 %
	Public policy	32	20.6 %
	Chronic Disease	5	3.2 %
	Total	154	n/a

*multiple answers; *N*=155

the most common primary source of learning. Genetic counseling training program was the most common secondary source of learning.

(1) Population-Based Screening Programs

Seventy participants (45 %) reported having job responsibilities related to a population-based screening program. Approximately one-fifth of total respondents spent more than 40 % of their time in public health roles. Of these (*n*=24), the following number participated in activities related to population-based screening programs: 11 (46 %) interpreted results of screening tests, 10 (42 %) notified health care providers of patients' screening test results, 8 (33 %) notified patients/parents of their/child's screening test results, and 6 (25 %) coordinated screening programs. There was no significant difference between those who did or did not coordinate screening programs and the average number of years worked (*p*=0.985).

(2) Education of Public and/or Health Care Providers

Almost half of participants reported being involved in at least one activity related to education of the public and/or health care providers.

(3) Lobbying/Public Policy

Of note, this section of the survey specifically asked participants not to include activities associated with genetic counselor licensure. These activities would have been higher-than-usual during the survey period, given that many states at the time were developing and/or considering genetic counselor licensure bills. The survey aimed to capture the lobbying/public policy activities of genetic counselors beyond those associated with genetic counselor licensure. Sixty-two

participants (40 %) reported involvement in at least one activity related to lobbying and public policy (Table 5).

(4) Public Health Related Research

Forty-seven participants (30 %) reported involvement in at least one activity related to public health related research (Table 6).

(5) State Chronic Disease Programs

Twelve participants (8 %) reported involvement in at least one activity related to state programs for chronic disease with a genetic component (Table 7).

Grouped by Public Health Category, participants reported the skills required to perform each public health related activity, plus the most influential source of learning for each skill (Tables 3, 4, 5, 6 and 7).

Discussion

Several studies have indicated that genetic counselors are participating in public health roles and activities, yet there is a lack of empirical information about the specific skills needed to perform these activities and where genetic counselors learn the related skills (Powell et al. 2010; NSGC 2008, 2010, 2012b). Only genetic counselors who spend at least 50 % of their time on public health activities are identified as "public health genetic counselors" by the NSGC PSS, since the PSS asks for the specialty in which participants spend 50 % or more of their time. Therefore, while the NSGC's PSS does provide some information about public health activities,

Table 3 Activities, Skills, and Sources of Learning for Population-Based Screening Programs ($n=70$)

Activity ($n, \%$)	Skill	Participants who use the skill, n (%)	Primary source for learning the skill ($n, \%$)	Secondary source for learning the skill ($n, \%$)
Interpret results of screening tests (56, 80 %)	Review patient demographics for accuracy of report interpretation	55 (98 %)	GC training program (27, 49 %)	On the job (19, 35 %)
	Assess concordance between raw testing values and final laboratory interpretation	42 (75 %)	GC training program (22, 52 %)	On the job (11, 26 %)
Notify health care providers about patients' screening test results (47, 67 %)	Communicate with health care providers about the importance of an immediate clinical follow-up	47 (100 %)	On the job (19, 40 %)	GC training program (12, 26 %)
	Identify the current primary care provider	45 (96 %)	On the job (24, 51 %)	GC training program (8, 18 %)
Notify patients/parents of their/child's screening test result (43, 61 %)	Communicate with patients/ parents about the importance of an immediate clinical follow-up	43 (100 %)	GC training program (19, 44 %)	On the job (17, 40 %)
	Identify current contact information for patient/parent	41 (95 %)	On the job (21, 51 %)	GC training program (9, 22 %)
	Work with an interpreter to disclose results	39 (91 %)	GC training program (27, 63 %)	On the job (11, 28 %)
Coordinate a screening program (10, 14 %)	Use information technology to collect data	9 (90 %)	On the job (4, 44 %)	GC training program, Formal training from employer ($n=2$ each, 22 %)
	Use information technology to store data	9 (90 %)	On the job (4, 44 %)	Formal training from employer (3, 33 %)
	Evaluate effectiveness and quality of programs	9 (90 %)	On the job (4, 44 %)	GC training program, Other degree/certificate program ($n=2$ each, 22 %)
	Use information technology to retrieve data	8 (80 %)	On the job (5, 63 %)	Formal training from employer (2, 25 %)
	Identify benefits, risks, and costs of screening to target population	6 (60 %)	GC training program (2, 33 %)	GC training program (2, 33 %)
	Supervise screening program staff	5 (50 %)	On the job (3, 60 %)	PH colleagues, Formal training from employer ($n=1$ each, 20 %)
	Develop standardized language for laboratory report interpretation	5 (50 %)	Formal training from employer (2, 40 %)	GC training program, On the job, Other ($n=1$ each, 20 %)
	Create budget priorities for the program	4 (40 %)	GC colleagues, Formal training from employer, On the job, Other ($n=1$ each, 25 %)	
	Develop criteria for adding/removing tests from the state NBS panel	4 (40 %)	PH colleagues (2, 50 %)	Other degree/certificate program, On the job ($n=1$ each, 25 %)
	Develop criteria for adding/removing tests from the GWAS panel	3 (30 %)	Other (2, 67 %)	On the job (1, 33 %)

GC=Genetic Counseling

PH=Public Health

a more targeted study was needed to determine specifics about the types of activities and the skills required.

Given the current study's results, the number of genetic counselors performing public health activities is most likely higher than reported by the PSS. The study had significantly more participants who had worked for 20+ years, compared to the 2010 PSS ($p=0.000$), possibly indicating that either the PSS is missing a group of people with public health experience, or that genetic counselors with more experience are more likely to participate in public health activities. The results also suggest that genetic counselors who do not consider themselves to be "public health genetic counselors" still participate in public health activities. In addition, Table 2

provides an interesting look at the numbers of genetic counselors who spend considerable portions of their time on public health activities, and indicates that those who spend most of their time on public health activities actually participate in a wider range of activities. This is the first study assessing the number of genetic counselors participating in public health activities, the skills that they use to participate in those activities, and the sources of learning for those skills.

Five categories of public health activities were surveyed: (1) Population-Based Screening Programs, (2) Education of Public and/or Health Care Providers, (3) Lobbying/Public Policy, (4) Public Health Related Research, and (5) State Chronic Disease Programs. The most common category

Table 4 Activities, Skills, and Sources of Learning for Education of the Public and/or Health Care Providers ($n=80$)

Activity ($n, \%$)	Skill	Participants who use the skill, n (%)	Primary source for learning the skill ($n, \%$)	Secondary source for learning the skill ($n, \%$)
Participate in educational outreach to health care providers (58, 73 %)	Conduct training for providers about genetic programs/ initiatives	52 (90 %)	On the job (25, 48 %)	GC training program (16, 31 %)
	Present information about genetic programs/initiatives for media/non-peer review publications	47 (81 %)	On the job (25, 53 %)	GC training program (17, 36 %)
	Publish data in peer reviewed journals	31 (53 %)	On the job (12, 39 %)	GC training program (10, 32 %)
Participate in educational outreach to the public (48, 60 %)	Provide community lectures about genetic programs/initiatives	45 (94 %)	GC training program (21, 47 %)	On the job (16, 36 %)
	Present information about genetic programs/initiatives for media/non-peer reviewed publications	41 (85 %)	On the job (23, 56 %)	GC training program (11, 27 %)
	Create advertising tools	35 (73 %)	On the job (19, 54 %)	GC training program (6, 17 %)
	Publish data in lay publications	30 (63 %)	On the job (17, 57 %)	GC training program (6, 20 %)
Develop patient educational materials (47, 59 %)	Assess educational materials to determine readability	47 (100 %)	GC training program (19, 40 %)	On the job (16, 34 %)
	Create educational materials that are culturally appropriate to meet needs of patients/parents	46 (98 %)	GC training program (25, 54 %)	On the job (14, 30 %)
	Create educational materials at the recommended 6th-8th grade reading level to meet the needs of patients/parents	46 (98 %)	GC training program (20, 44 %)	On the job (17, 37 %)

GC=Genetic Counseling

reported by participants was education of public and/or health care providers (52 %), which is a component of the Practice-Based Competencies for Genetic Counselors (Accreditation Council for Genetic Counseling 2013). Genetic counselors have a unique perspective and knowledge base that makes them ideal for educating the public as well as other health care professionals (Collins and McInerney 2009). In NSGC's 2012 PSS, 63 % of participants reported creating patient education materials, 24 % developed a curriculum for students/teachers, 23 % developed or organized a conference, workshop, or symposium for health providers, and 12 % developed or organized a conference, workshop, or symposium for patients (NSGC 2012b). It is likely that these responses include both activities within and outside a public health context, which is impossible to tease apart based on the PSS data alone. However, we propose that while "non-public health" genetic counseling positions may focus on clinical activities, genetic counselors in these roles may also commit time towards public health education activities.

The second most common public health activity reported by participants pertained to population-based screening programs (45 %), specifically newborn screening or maternal serum screening. Genetic counselors have been associated with these screening programs for decades, so it is not surprising that maternal serum screening and newborn screening composed the vast majority of the screening programs in

which participants were involved. Supporting this are past PSS results showing 29–38 % of genetic counselors spend at least 50 % of their time in a prenatal setting, of which maternal serum screening is a major component (NSGC 2008, 2010, 2012a, b). This has consistently been the largest specialty area of genetic counselors. Given the history of genetic counselor involvement in prenatal care, it makes sense that genetic counselors may choose to use their clinical expertise and experience to develop public health skills within the context of a population-based screening program.

Relatively few participants reported job activities related to state chronic disease programs (8 %). The survey may not have fully captured the activities of genetic counselors working in state chronic disease programs/clinics, since participants were only asked about coordinating or creating a state program/clinic. Genetic counselors could potentially be involved in state chronic disease programs in other ways, such as providing professional and lay education, developing genetic testing policies, or participating in state-wide public health campaigns. Most of the skills related to "State Chronic Disease Programs" were learned someplace other than a genetic counselor training program ("on the job" and "other degree/certificate program" were the most common sources of learning for these skills). Given that the public health activities within this category were relatively high-

Table 5 Activities, Skills, and Sources of Learning for Lobbying/Public Policy ($n=62$)

Activity ($n, \%$)	Skill	Participants who use the skill, n (%)	Primary source for learning the skill ($n, \%$)	Secondary source for learning the skill ($n, \%$)
Serving on a committee focused on the delivery of local/state/national health or genetic services (31, 50 %)	Use procedures for addressing public health and genetics at a local/state/ regional/ national level	29 (94 %)	On the job (8, 28 %)	GC colleagues (7, 24 %)
	Evaluate the Impact of using genetic services in different populations	27 (87 %)	GC training program (9, 33 %)	On the job (9, 33 %)
	Evaluate the Determinants of using genetic tests in different populations	26 (84 %)	GC training program (12, 46 %)	On the job and PH colleagues ($n=5$ each, 19 %)
	Evaluate the Determinants of using genetic services in different populations	25 (81 %)	GC training program (9, 36 %)	PH colleagues (8, 32 %)
	Evaluate the Impact of using genetic tests in different populations	24 (77 %)	GC training program (12, 50 %)	PH colleagues (5, 21 %)
	Contribute to development of written committee report	23 (74 %)	On the job (9, 39 %)	PH colleagues (5, 22 %)
	Evaluate disease intervention strategies	19 (61 %)	On the job (7, 37 %)	PH colleagues (4, 21 %)
	Develop disease intervention strategies	19 (61 %)	On the job (7, 37 %)	PH colleagues (4, 21 %)
	Implement disease intervention strategies	16 (52 %)	On the job (9, 56 %)	PH colleagues (3, 19 %)
	Communicating with the press/media (24, 39 %)	Communicate key messages in media interviews	24 (100 %)	On the job (12, 50 %)
Participating in the development of genetics public policy/legislation (17, 27 %)	Communicate the role of public health genetics within the overall health system	22 (92 %)	On the job (11, 50 %)	PH colleagues; GC training program; other degree/certificate program ($n=3$ each, 14 %)
	Develop press releases	15 (63 %)	On the job (9, 60 %)	PH colleagues (3, 20 %)
	Read and understand current public policy/legislation documents	16 (94 %)	On the job (8, 50 %)	PH colleagues (4, 25 %)
	Synthesize literature, opinions and recommendations for publication of white paper	15 (88 %)	On the job (7, 47 %)	GC training program (2, 13 %)
	Utilize and understand legal terminology	14 (82 %)	On the job (7, 50 %)	Other (2, 14 %)
	Create policy statements for professional organization	10 (59 %)	On the job (5, 50 %)	Other (2, 20 %)
	Create policy statements for public health program	9 (53 %)	On the job (4, 44 %)	PH colleagues (3, 33 %)
	Prepare testimony for legislation	7 (41 %)	PH colleagues (3, 43 %)	On the job (2, 29 %)
	Present testimony for legislation	6 (35 %)	On the job, PH colleagues ($n=2$ each, 33 %)	GC colleagues, Other degree/ certificate program ($n=1$ each, 17 %)
	Draft a bill	4 (24 %)	PH colleagues; Other degree/certificate program; On the job, Other ($n=1$ each, 25 %)	
Assessment of state genetic resources or needs to determine future goals and strategies (17, 27 %)	Contribute to development of written report of needs assessment	15 (88 %)	On the job (4, 27 %)	PH colleagues, GC training program, Other degree/certificate program ($n=3$ each, 20 %)
	Create assessment tools	15 (88 %)		

Table 5 (continued)

Activity (<i>n</i> , %)	Skill	Participants who use the skill, <i>n</i> (%)	Primary source for learning the skill (<i>n</i> , %)	Secondary source for learning the skill (<i>n</i> , %)	
Provide comment on existing policies for insurers/payers (16, 26 %)	Analyze qualitative assessment results	14 (82 %)	GC training program, PH colleagues (<i>n</i> =4 each, 27 %) GC training program; On the job (<i>n</i> =4 each, 29 %)	Other degree/certificate program, On the job (<i>n</i> =3 each, 20 %) PH colleagues, Other degree/certificate program (3, 21 %)	
	Analyze quantitative assessment results	14 (82 %)	GC training program (5, 36 %)	PH colleagues, Other degree/certificate program, On the job (<i>n</i> =3 each, 21 %)	
	Develop methods for initial assessment	14 (82 %)	GC training program (5, 36 %)	On the job (4, 29 %)	
	Read and understand current policies	16 (100 %)	On the job (7, 44 %)	GC training program (5, 31 %)	
	Synthesize relevant literature, opinion and recommendations	16 (100 %)	GC training program (10, 63 %)	On the job (3, 19 %)	
	Locate current policies	15 (94 %)	On the job (8, 53 %)	GC training program (4, 27 %)	
	Create model policy statements for insurers	8 (50 %)	On the job (4, 50 %)	PH colleagues (2, 25 %)	
	Demonstrate effective public speaking skills	14 (100 %)	On the job (4, 29 %)	Other (4, 29 %)	
	Convey genetic, medical and technical information to a variety of audiences	14 (100 %)	GC training program (8, 57 %)	On the job (3, 21 %)	
	Develop talking points	12 (86 %)	PH colleagues, Professional meeting, Other (<i>n</i> =2 each, 14 %)	GC colleagues, GC training program, Other degree/certificate program, Formal training from employer, Unsture (<i>n</i> =1 each, 7 %)	
Communicating with senators/representatives (14, 23 %)	Establish partnerships with key stakeholders	12 (86 %)	On the job (6, 50 %)	PH colleagues, Other (<i>n</i> =2 each, 17 %)	
	Communicate the role of public health genetics within the overall system	11 (79 %)	On the job (5, 46 %)	GC training program (2, 18 %)	
	Identify champions within the legislative system	11 (79 %)	On the job (4, 36 %)	Other (3, 27 %)	
	Locate current policies	4 (100 %)	GC colleagues, PH colleagues, GC colleagues, GC training program, On the job (<i>n</i> =1 each, 25 %)	Other (3, 27 %)	
	Comprehend current policies	4 (100 %)	GC colleagues, PH colleagues, GC training program, Other degree/certificate program (<i>n</i> =1 each, 25 %)	Other degree/certificate program, Other degree/certificate program (<i>n</i> =1 each, 25 %)	
	Synthesize relevant literature, opinions and recommendations	4 (100 %)	GC training program (2, 50 %)	PH colleagues, On the job (<i>n</i> =1 each, 25 %)	
	Create model policy statements for insurers	4 (100 %)	On the job (2, 50 %)	PH colleagues, Other degree/certificate program (<i>n</i> =1 each, 25 %)	
	Create policies for insurers/payers (4, 7 %)				

GC=Genetic Counseling

PH=Public Health

Table 6 Activities, Skills, and Sources of Learning for Public Health Related Research, (*n*=47)

Activity (<i>n</i> , %)	Skill	Participants who use the skill, <i>n</i> (%)	Primary source for learning the skill (<i>n</i> , %)	Secondary source for learning the skill (<i>n</i> , %)
Develop qualitative assessment tools (27, 57 %)	Conduct a literature review	27 (100 %)	GC training program (16, 59 %)	On the job (6, 22 %)
	Develop IRB submission	24 (89 %)	On the job (9, 38 %)	GC training program (6, 25 %)
	Evaluate existing tools for validity and meaning of results	23 (85 %)	On the job (10, 44 %)	Other degree/certificate program (4, 17 %)
	Collaborate with statisticians to validate data collection tools	22 (82 %)	On the job (10, 46 %)	GC training program (6, 27 %)
Participate in data analysis (26, 55 %)	Collaborate with survey experts to validate data collection tools	18 (67 %)	On the job (7, 39 %)	GC training program, Other degree/certificate program (<i>n</i> =4 each, 22 %)
	Consult with statisticians	25 (96 %)	On the job (14, 56 %)	GC training program, Other degree/certificate program (4, 16 %)
	Analyze quantitative assessment results	25 (96 %)	GC training program (9, 36 %)	On the job (7, 28 %)
Participate in grant writing (24, 51 %)	Analyze qualitative assessment results	24 (92 %)	GC training program (9, 38 %)	On the job (7, 29 %)
	Rectify gaps in data sources	24 (92 %)	On the job (9, 38 %)	GC training program (5, 21 %)
	Employ statistical software for data analysis	22 (85 %)	On the job (7, 32 %)	GC training program (6, 27 %)
	Conduct relevant literature review	24 (100 %)	GC training program (12, 50 %)	On the job (8, 33 %)
	Articulate research goals	24 (100 %)	On the job (12, 50 %)	GC training program, Other degree/certificate program (<i>n</i> =4 each, 17 %)
Participate in grant administration (22, 47 %)	Describe methods, activities and timeline	24 (100 %)	On the job (11, 46 %)	Other degree/certificate program (5, 21 %)
	Develop justified budget for the project	23 (96 %)	On the job (14, 61 %)	Formal training from employer (5, 22 %)
	Monitor project timeline	20 (90 %)	On the job (15, 75 %)	Other degree/certificate program (2, 10 %)
Ensure that IRB-approved protocols are followed	Monitor grant expenditures	19 (86 %)	On the job (7, 37 %)	IRB training session (6, 32 %)
	Compile findings into report or manuscript form	18 (82 %)	On the job (14, 78 %)	PH colleagues (2, 11 %)
		18 (82 %)	On the job (14, 78 %)	GC colleagues, PH colleagues, GC training program, Other degree/certificate program (<i>n</i> =1 each, 6 %)
Create regular reports to granting agency	Present findings at professional meetings	17 (77 %)	On the job (12, 71 %)	Formal training from employer (2, 12 %)
	Publish findings in peer-reviewed journals	15 (68 %)	On the job (7, 47 %)	GC colleagues (3, 20 %)
		15 (68 %)	On the job (8, 53 %)	GC colleagues, PH colleagues, GC training program (<i>n</i> =2 each, 13 %)

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Table 7 Activities, Skills, and Sources of Learning for State Chronic Disease Programs ($n=12$)

Activity (n , %)	Skill	Participants who use the skill, n (%)	Primary source for learning the skill (n , %)	Secondary source for learning the skill (n , %)
Coordinating a state clinic (7, 58 %)	Communicate protocol, services, and patient information with clinic members	7 (100 %)	On the job (4, 57 %)	GC training program (2, 29 %)
	Use IT to collect data	6 (86 %)	On the job (3, 43 %)	GC training program, Other degree/certificate program, IRB training session ($n = 1$ each, 17 %)
	Use IT to store data	6 (86 %)	GC training program (2, 33 %)	GC colleagues, Other degree/certificate program, On the job, IRB training session ($n = 1$ each, 17 %)
	Use IT to retrieve data	6 (86 %)	On the job (2, 33 %)	GC colleagues, PH colleagues, GC training program, Other degree/certificate program ($n = 1$ each, 17 %)
	Evaluate clinic effectiveness and quality	6 (86 %)	On the job (3, 50 %)	PH colleagues, Other degree/certificate program, Formal training from employer ($n = 1$ each, 17 %)
	Supervise clinic staff	6 (86 %)	On the job (4, 67 %)	Other degree/certificate program, Formal training from employer ($n = 1$ each, 17 %)
	Work with health care specialists to coordinate clinic times/dates	6 (86 %)	On the job (3, 50 %)	GC training program, Other degree/certificate program, Formal training from employer ($n = 1$ each, 17 %)
	Implement clinic protocol/standard of care	6 (86 %)	On the job (5, 83 %)	Other degree/certificate program (1, 17 %)
	Negotiate with hospitals/clinics for locations/services	5 (71 %)	On the job (4, 80 %)	Other degree/certificate program (1, 20 %)
	Apply intervention strategies for diseases with genetic components	5 (71 %)	On the job (2, 40 %)	GC training program, Other degree/certificate program, Professional meeting ($n = 1$ each, 20 %)
Coordinating a state program (4, 33 %)	Evaluate program effectiveness and quality	4 (100 %)	PH colleagues; Other degree/certificate program; On the job; Researchers, physicians or lab directors ($n=1$ each, 25 %)	
	Supervise program staff	4 (100 %)	PH colleagues (2, 50 %)	Other degree/certificate program, On the job ($n = 1$ each, 25 %)
	Communicate protocol, services, and patient information with program members	4 (100 %)	PH colleagues, Other degree/certificate program, Formal training from employer, On the job ($n=1$ each, 25 %)	
	Implement program protocol	4 (100 %)	PH colleagues, Other degree/certificate program, Formal training from employer, On the job ($n=1$ each, 25 %)	
	Use IT to collect data	3 (75 %)	Other degree/certificate program, Formal training from employer, On the job ($n=1$ each, 33 %)	
	Use IT to store data	3 (75 %)	Other degree/certificate program, Formal training from employer, On the job ($n=1$ each, 33 %)	
	Use IT to retrieve data	3 (75 %)	Other degree/certificate program, Formal training from employer, On the job ($n=1$ each, 33 %)	

Table 7 (continued)

Activity (<i>n</i> , %)	Skill	Participants who use the skill, <i>n</i> (%)	Primary source for learning the skill (<i>n</i> , %)	Secondary source for learning the skill (<i>n</i> , %)
Creation of a state program (2, 17 %)	Manage program budget priorities	3 (75 %)	PH colleagues, Other degree/certificate program, On the job (<i>n</i> =1 each, 33 %)	Other degree/certificate program (1, 100 %)
	Apply intervention strategies for diseases with genetic components	1 (25 %)	Other degree/certificate program (1, 100 %)	
	Identify benefits, risks, and costs of screening to target population	2 (100 %)	Other degree/certificate program, On the job (<i>n</i> =1 each, 50 %)	
	Create program budget priorities	1 (50 %)	Other degree/certificate program (1, 100 %)	
	Develop methods for needs assessment	1 (50 %)	Other degree/certificate program (1, 100 %)	
	Create needs assessment tools	1 (50 %)	Other degree/certificate program (1, 100 %)	
	Analyze qualitative assessment results	1 (50 %)	Other degree/certificate program (1, 100 %)	
	Analyze quantitative assessment results	1 (50 %)	Other degree/certificate program (1, 100 %)	
	Develop principles for population-based screening programs	1 (50 %)	Other degree/certificate program (1, 100 %)	
	Develop intervention strategies for diseases with genetic components	1 (50 %)	Other degree/certificate program (1, 100 %)	
	Contribute to written report of needs assessment	1 (50 %)	Other degree/certificate program (1, 100 %)	
	Develop program protocol/standard of care	1 (50 %)	Other degree/certificate program (1, 100 %)	
	Creation of a state clinic (2, 17 %)	Develop methods for needs assessment	2 (100 %)	Other degree/certificate program, On the job (<i>n</i> =1 each, 50 %)
Create needs assessment tools		2 (100 %)	Other degree/certificate program, On the job (<i>n</i> =1 each, 50 %)	
Analyze qualitative assessment results		2 (100 %)	GC colleagues, Other degree/certificate program (<i>n</i> =1 each, 50 %)	
Analyze quantitative assessment results		2 (100 %)	GC colleagues, Other degree/certificate program (<i>n</i> =1 each, 50 %)	
Develop intervention strategies for diseases with genetic components		2 (100 %)	Other degree/certificate program, On the job (<i>n</i> =1 each, 50 %)	
Develop clinic protocol/standard of care		2 (100 %)	GC colleagues, Other degree/certificate program (<i>n</i> =1 each, 50 %)	
GC=Genetic Counseling				
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level (creating or coordinating a state program), one can assume that they would not be entry level positions. Therefore, a genetic counselor involved in these activities likely has experience within the public health system and has expanded their skill set appropriately, through on-the-job learning and/or educational opportunities, to supplement their genetic counseling training. This is an area where more investigation would be needed to help clarify the extent that genetic counselors are participating in this area, their roles, and the skills utilized for these positions.

Not surprisingly, most of the skills related to “Lobbying/Public Policy” were reportedly learned on the job. With limited time and increasing curriculum requirements in genetic counseling training programs, these skills may not be a priority and genetic counseling students may have limited exposure to them. Of interest, only 9 % of participants reported communicating with senators/representatives about public health programs or initiatives involving genetics in the last year, similar to the low number of individuals who reportedly started state programs. While the data did not reveal if these were exactly the same individuals, it stands to reason that individuals who need to obtain funding and/or support for starting a state program will interact with their state representatives more than genetic counselors would otherwise. Similarly, few participants had communicated with the press/media about health programs involving genetics (15 %) or had participated in the development of genetics policy/legislation (11 %). It would be beneficial for the field to identify individuals with experience in these areas so as to utilize their experience, especially as we move forward with NSGC branding, representing our professional society, marketing our services, and lobbying for recognition by payors.

Of particular interest to genetic counseling training program directors, or those considering starting training programs, are the results showing the most influential source of learning for various skills. If a genetic counseling training program aims to have a strong public health training component, it should look to include opportunities to learn these skills in greater depth. For example, in the Public Health Research category, 27 participants (17.4 %) reported developing qualitative assessment tools focused on public health initiatives in the past year. The majority indicated that the most influential source of learning for the five associated skills was their place of employment (with the exception of literature review, which was learned mainly in a genetic counseling training program). The skills (developing an IRB submission, evaluating tools for validity, collaborating with statisticians, and collaborating with survey experts) are ones commonly thought to be learned and practiced during genetic counseling students’ thesis projects, yet the study sample shows that participants’ genetic counseling training programs were not their most influential source of learning. This could indicate a need to appropriate more time or energies towards these

particular skills in graduate training of genetic counselors, particularly if we aim to increase the number of quality research publications stemming from student theses.

One option for genetic counseling training programs wishing to strengthen their public health component is to recruit students with public health/legislative/communications backgrounds. Rather than focusing on training genetic counselors to be public health figures, programs could identify applicants with public health backgrounds and utilize their skill set while training them as genetic counselors. Training programs could also encourage students to explore rotations/internships where they can learn about roles in public health, policy-making, legislation, and business/communications. Our field is growing rapidly, and giving students an opportunity to explore these areas behooves us. Finally, genetic counselors should encourage the NSGC to continue providing trainings, particularly for those types of skills/education that genetic counselors feel they do not receive through their genetic counseling training programs.

Overall, the most influential source of learning skills in all categories was “on the job,” followed by “genetic counseling training programs.” These results suggest that genetic counselors may be introduced to and initially learn a skill set in their training programs, and that this enables them to continue to learn and acquire public health skills “on the job”. It appears as though genetic counseling training programs provide a solid foundation from which genetic counselors can add greater depth and nuance to their skills base and learn further how to translate those skills to public health activities.

Further research could look at the experiences of genetic counselors who have completed one of the public health genetics certificate programs offered at various universities, to assess the influence of additional, targeted training on those individuals’ public health skill sets. A future study could assess if there have been changes in general NSGC members’ participation in public health activities, skills used, and sources of learning for those skills.

Study Limitations

There are several limitations associated with this study, including the relatively small sample size ($N=155$) and the potential selection bias of genetic counselors who self-identify as “public health genetic counselors” to complete the survey. The sample size may have been increased by leaving the survey link open longer, or by using other avenues to reach more genetic counselors performing public health activities (such as the ABGC general member contact list or contacting state genetic coordinators directly). The length and detail of the survey also made it potentially cumbersome, especially if participants were involved in multiple public health activities. This limitation is indicated by the 43 individuals who started the survey but did not complete it. The study may have been better done in stages, starting with a survey about public

health activities and following up with a survey about associated skills and sources of learning. The survey did not include a definition of public health, which may have biased the results as participants may have had different views as to what the questions were assessing. While the survey did not include a general definition of skill, each public health skill was specified and described. Finally, the survey asked participants to estimate their time spent on public health activities in the following categories: 1–20 %, 21–40 %, 41–60 %, 61–80 %, and 81–100 %. These groupings did not exactly correspond to the PSS for comparison purposes (the PSS asks for >50 % time), which could be a limitation, but which was purposefully done so as to identify groups participating in public health activities that would not be captured by the PSS.

Conclusion

Overall, this study highlighted the public health activities in which genetic counselors participate, identified the specific skills used during those activities, and determined the sources of learning for those skills. Genetic counselors who may not consider themselves “public health genetic counselors” may be surprised at the number of skills they employ that could fall within the realm of a public health function, and by the potential overlap between non-public health genetic counseling and public health genomics. Genetic counselors learn a diverse skill set in their training programs. Some of those skills are directly applicable to public health genetics, while other public health skills require additional practice/experience, training, and/or knowledge.

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Conflict Of Interest Authors Kirsty M. McWalter, Mallory R. Sdano, Gaurav Dave, Karen P. Powell and Nancy Callanan declare that they have no conflict of interest.

Human Studies and Informed Consent All procedures performed involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent was obtained from all individual participants included in the study.

Animal Studies This article does not contain any studies with animals performed by any of the authors.

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