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Genetic counseling workforce diversity, inclusion, and capacity in Australia and New Zealand



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ABSTRACT

Purpose: To understand diversity, inclusion, and capacity of genetic counselors (GCs) in Australasia (Australia and New Zealand).

Methods: Individuals with or working toward a GC qualification in Australasia were invited to complete an online survey, between November 2022 and March 2023. Quantitative data were analyzed using descriptive statistics, 1-sample proportion z-tests, 2-sample z-tests, and χ^2 tests. Qualitative data were analyzed using inductive content analysis.

Results: A total of 252 participants responded to the survey. A subset analysis of respondents residing in Australia demonstrated a lack of representation across various characteristics including sex, relationship status, caregiver status, location, country of birth, Aboriginal/Torres Strait Islander identity, language, and religion. Analysis of the full data set demonstrated that most respondents also perceived that the workforce was not representative across gender, sexual orientation, ethnicity, or disability. Respondents provided examples of existing inclusive practice. They also suggested workforce needs, such as promoting education and employment for minority communities, more visible diversity, accessible services for clients, and professional development for GCs. Using survey and reference data, we estimated approximately 346 full-time equivalent GCs working in clinical practice in Australasia.

Conclusion: Our study provides a first step in illuminating GC workforce changes needed in Australasia regarding diversity, inclusion, and capacity. The survey may be of use internationally, enabling other countries to understand these issues within their jurisdiction, and supporting the international community in addressing these challenges.

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The names of the 2023 HGSA Workforce Surveys Steering Committee and the ASGC DICE Working Group members will appear at the end of the article.

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Introduction

Genetic counselors (GCs) play an important role in delivering genomic medicine.¹ It is imperative that this workforce is able to foster diversity and inclusion both for the workforce itself and to provide equitable care for a diverse range of clients.² At the broader level, there must be sufficient workforce to meet growing service demand.

Having a diverse health care provider workforce may reduce health disparities, improve access to services, foster cultural competency, facilitate client-provider communication, improve health and research outcomes, and enhance client satisfaction.²⁻⁶ A diverse and representative GC workforce is one that reflects the varied demographics of the population, such as gender, sexual orientation, immigration status, disability, and socioeconomic factors.² Despite the benefits, evidence from North America and Australia suggest lack of diversity in the GC workforce.^{2,7,8} In 2022 the National Society of Genetic Counselors membership in North America was primarily made up of people who identify as women, under 45 years old, heterosexual, European descent, and not having a disability.⁷ A similar lack of diversity has been reflected in Australian GCs in relation to age and gender.⁸ However, the characteristics of the GC profession beyond this are currently unclear.

Another important priority is inclusion both for clients and the GC workforce. Clients from marginalized groups may face health care inequities, such as poorer access to services, lack of adequate information and support, and discrimination.⁹⁻¹³ Similarly, GCs from marginalized groups may have poorer professional experiences, such as later introduction to the field, discrimination, navigating unique challenges, and feeling internal or external pressure to be a “diversity expert.”^{4,14} These issues highlight the importance of GCs, working in a way that is person centered, effective, and equitable for everyone in the population.^{15,16} Promoting GC workforce diversity and inclusion is a key strategic goal of the Australasian Society of Genetic Counsellors (ASGC)¹⁷ and a priority internationally.^{5,18,19} The ASGC is the professional body for GCs in Australia and New Zealand (collectively termed here “Australasia”). Promoting diversity and inclusion requires an understanding of current workforce characteristics and practice; however, these data are currently unavailable. Therefore, we aimed to assess the current demographics of the workforce, understand GC experiences of inclusion for the workforce and clients, and identify opportunities for improvement.

Alongside diversity and inclusion, the workforce must also be able to meet general clinical demand. In 2018, it was estimated that there were approximately 7000 GCs worldwide, practicing in at least 28 countries.¹ Ample interna-

tional evidence demonstrates a shortage of genetic health care providers across the globe.^{1,20-23} The Australian Genomics Health Alliance was established in 2016 to facilitate integration of genomic medicine into the health care system. In 2017, Australian Genomics partnered with the ASGC to conduct a census of Australasian genetic health care providers’ education, practice, capacity, and readiness to provide genomic medicine.⁸ Approximately two-thirds (65.9%) of GCs who responded to the 2017 census were employed in a clinical role, and 14% planned to retire by 2027.⁸ Using data provided by current and previous Master of Genetic Counseling course conveners, it was estimated that there were approximately 480 individuals with a GC qualification working in Australasia at that time. ASGC membership data indicated approximately 220 working in clinical roles.⁸

Workforce capacity is of concern because of already existing demand and wait times of over 1 year for appointments at many genetic services.²⁴⁻²⁶ GC demand may continue to rise because of drivers such as technological advancements, health system goals for mainstreaming genetics, increasing recognition of the GC role, and growth in genomics research.²⁶ Therefore we aimed to reassess the capacity of the GC workforce to meet demand in Australasia.

To address these key contemporary workforce issues, we conducted a census survey of the GC workforce in Australasia. In addition to obtaining an up-to-date understanding of current demographics and workforce capacity, our primary aims were to understand the perceived representation, perspectives on providing inclusive care, and opportunities to support diversity and inclusion for the workforce and population they serve.

Materials and Methods

A national online survey of the genetics workforce in Australasia was conducted as a collaboration by the Human Genetics Society of Australasia (HGSA) Workforce Survey Steering Committee, the ASGC Diversity, Inclusion, Cultural Competency, and Equity (DICE) Working Group, and the Australian Genomics Workforce and Education program.

Survey design

The survey is an expanded version of the 2017 census of the Australian GC and clinical genetics workforce (Supplemental Item 1).⁸ Questions were also sourced and adapted from the National Society of Genetic Counselors Professional Status Survey,⁷ HGSA and ASGC membership data (personal communications with ASGC representative), and

other surveys relating to workforce capacity and diversity (cited in Supplemental Item 1). Questions were identified, adapted, and iteratively reviewed by the HGSA Workforce Survey Steering Committee and ASGC DICE working group. Surveys were piloted with members of the HGSA Workforce Survey Steering Committee and revised based on feedback. Domains included demographics, diversity and inclusion, qualifications and accreditation, employment, including clinical practice, continuing professional development, and feedback on the ASGC as the representative professional body. The survey included single or multi-choice questions, Likert scales, and open-ended questions. The survey was hosted on the Murdoch Children's Research Institute's instance of REDCap.^{27,28} Response numbers vary by question because of branching logic, overlapping categories, and/or missing data.

Sample and recruitment

Eligibility criteria included people whose primary profession, qualification, or study was genetic counseling in Australasia. The survey was advertised via professional society newsletters, professional networks, and snowball sampling. Respondents were provided with information about the study, consented at the beginning of the survey, and could stop participating at any point before completion.

Data cleaning and analysis

Data cleaning, quality checking, and analysis were conducted in Microsoft Excel, Epitools epidemiological calculators,²⁹ and STATA18.³⁰ Incomplete surveys were only included in data analysis if they included responses to all questions in section 1 "Qualification, accreditation and professional membership." Missing data are acknowledged by reporting sample sizes for individual questions. Duplicate records were identified and removed if numerous respondent characteristic responses were identical or if respondents informed the study team that they accessed the survey twice. Open-text responses to "Other" options were coded into existing categories within the relevant variables if appropriate.

Quantitative data were analyzed using descriptive statistics, 1-sample proportion *z*-tests, and 2-sample *z*-tests to compare sample proportions of metric data, and χ^2 tests to compare categorical data. Comparisons were not conducted for any categories in which the number of respondents was less than 5. Reference data used in analyses included ASGC membership registration data (personal communications with ASGC representative), Master of Genetic Counseling graduate numbers (personal communications with Master of Genetic Counseling course conveners), and data from the 2017 census, which was also performed by our research group (C.G. and A.N.).⁸ A subset analysis was conducted on respondents residing in Australia to assess workforce representation. State and remoteness level for respondents in

Australia were determined by matching postcode data to postcode remoteness levels from the Australian Bureau of Statistics.^{31,32} Australian population data or estimates were used as comparators where available.³³⁻⁴⁷ Our data set was not compared with New Zealand population data because of a small number of respondents residing in New Zealand. A *P* value of < .05 was considered statistically significant.

Qualitative data were analyzed using inductive content analysis and are presented descriptively with frequencies where appropriate.⁴⁸ Frequencies may exceed the total number of responses as some comments included more than 1 concept.

Results

Respondent characteristics

The survey was conducted between November 2022 and March 2023. Of 493 GCs who were members of ASGC, 246 (50%) responded to the survey, including 2 students. Six people with a GC qualification who were not ASGC members also responded to the survey, resulting in a total of 252 respondents. Respondent characteristics are displayed in Table 1.

Respondents resided in Australia (232/247, 93.9%), New Zealand (14/247, 5.7%), and South-East Asia (1/247, 0.4%). The participant residing in South-East Asia was included in analysis because they were employed in Australia. Respondents primarily identified as women (91.9%), heterosexual (84.2%), married (49.4%), between 25 and 45 years of age (71.8%), based in metropolitan Australia (85.4%), and born in Australia (71.3%). Most were not primary caregivers for children (57.6%), not carers (86.1%), did not use any languages other than English proficiently (81%), did not identify as Aboriginal and/or Torres Strait Islander (99.2%), did not identify as Māori (99.2%), and did not report a disability (89.0%).

Respondents were compared with ASGC membership in relation to gender, age, location, Māori identity, Aboriginal, and Torres Strait Islander identity. Differences were observed among people aged 20 to 25 (4.6% vs 16.9%, *P* < .001), residing overseas (0.4% vs 4.7%, *P* = .002), and not identifying as Māori (99.2% vs 96.5%, *P* = .042).

A subset analysis of respondents residing in Australia demonstrated differences across several characteristics (Supplemental Table 2). Respondents were more likely than the employed population to be aged between 25 and 34 years old (37.4% vs 25.4%, *P* < .001),³³ or aged between 35 and 44 years old (34.2% vs 24.9%, *P* = .001).³³ Compared with the general Australian population, respondents were more likely to be assigned female at birth (92.2% vs 50.7%, *P* < .001),³⁴ living in Victoria (37% vs 25.6%, *P* < .001),³⁹ living in a major city (93.4% vs 72.2%, *P* < .001),⁴⁰ not identifying as Aboriginal and/or Torres Strait Islander (99.1% vs 96.6%, *P* = .035),⁴¹ born in New Zealand (4.7%

Table 1 Respondent characteristics

Characteristics	Categories	<i>n</i> (%)
Age (<i>N</i> = 237)	20-24	11 (4.6)
	25-34	90 (38.0)
	35-44	80 (33.8)
	45-54	37 (15.6)
	55-64	19 (8.0)
Gender ^a (<i>N</i> = 247)	Woman or female	227 (91.9)
	Man or male	19 (7.7)
	Other Gender	0 (0.0)
	Prefer not to answer	1 (0.4)
Sex ^a (<i>N</i> = 247)	Female	226 (91.5)
	Male	19 (7.7)
	Other Sex	0 (0.0)
	Prefer not to answer	2 (0.8)
Sexual Orientation (<i>N</i> = 247)	Heterosexual	208 (84.2)
	Bisexual, Gay, or Lesbian	22 (9.1)
	A different term ^b	5 (2.0)
	Don't know	2 (0.8)
	Prefer not to answer	10 (4.0)
Relationship Status (<i>N</i> = 247)	Registered married	122 (49.4)
	Never married/de facto	54 (21.9)
	De facto	48 (19.4)
	Divorced	7 (2.8)
	Separated but not divorced	5 (2.0)
	Engaged	2 (0.8)
	Widowed	2 (0.8)
	Prefer not to answer	7 (2.8)
Primary caregiver for child(ren) (<i>N</i> = 245)	No	141 (57.6)
	Yes	104 (42.4)
Country of residence (<i>N</i> = 247)	Australia	232 (93.9)
	New Zealand	14 (5.7)
	Malaysia	1 (0.4)
State/Territory (Australia only) (<i>N</i> = 227)	Victoria	84 (37.0)
	NSW	71 (31.3)
	Western Australia	23 (10.1)
	South Australia	19 (8.4)
	Queensland	17 (7.5)
	ACT	7 (3.1)
	Tasmania	6 (2.6)
	Northern territory	0 (0.0)
Remoteness (Australia only) (<i>N</i> = 226)	Major cities	211 (93.4)
	Inner regional	14 (6.2)
	Outer regional	1 (0.4)
	Remote/very remote	0 (0.0)
Aboriginal/Torres Strait Islander identity (<i>N</i> = 247)	Aboriginal	1 (0.4)
	Torres Strait Islander	0 (0.0)
	Both	0 (0.0)
	Unsure	1 (0.4)
	Neither	243 (98.4)
Māori identity (<i>N</i> = 247)	Prefer not to answer	0 (0.0)
	Māori	2 (0.8)
	Unsure	0 (0.0)
	Not Māori	245 (99.2)
	Prefer not to answer	0 (0.0)

(continued)

Table 1 Continued

Characteristics	Categories	<i>n</i> (%)
Country of Birth (<i>N</i> = 247)	Australia	176 (71.3)
	New Zealand	18 (7.3)
	England	11 (4.5)
	Canada	7 (2.8)
	South Africa	5 (2.0)
	United States of America	4 (1.6)
	Malaysia	3 (1.2)
	Other ^c	22 (8.9)
	Prefer not to answer	1 (0.4)
Generation in country of residence ^d (<i>N</i> = 246)	Third+	126 (51.2)
	Second	57 (23.2)
	First	62 (25.1)
	Prefer not to answer	1 (0.4)
Year of migration (<i>N</i> = 59)	Before 2016	51 (86.4)
	2016-2021	8 (13.6)
Languages used proficiently (<i>N</i> = 247)	English only	200 (81.0)
	English very well or well, and other language ^e	47 (19.0)
	English not well or at all, and other language	0 (0.0)
Religion (<i>N</i> = 243)	No Religion	155 (63.8)
	Christianity	63 (25.9)
	Judaism	12 (4.9)
	Buddhism	4 (1.6)
	Hinduism	3 (1.2)
	Islam	0 (0.0)
	Other religions ^f	1 (0.4)
	Prefer not to answer	5 (2.1)
Disability Status (<i>N</i> = 245)	No	218 (89.0)
	Yes ^g	22 (9.0)
	Prefer not to answer	5 (2.0)
Carer status (<i>N</i> = 244)	No	210 (86.1)
	Yes	34 (13.9)

^aTwo respondents indicated a difference between their sex and gender.^bDifferent terms for sexual orientation included pansexual, asexual and being married to a person of the same gender.^cOther countries of birth include countries selected by 1 or 2 respondents: Bolivia, Brazil, France, India, Indonesia, Ireland, Israel, Japan, Macedonia, Netherlands, Papua New Guinea, Singapore, Taiwan, Zimbabwe, Scotland, UAE, and Unspecified.^dFirst generation refers to people born outside their country of residence. Second generation refers to people who are born in their country of residence and have 1 or more parents born outside country of residence. Third+ generation refers to people born in their country of residence with both parents also born in their country of residence.^eOther languages used in order of frequency were French, Italian, Mandarin, Spanish, Cantonese, Afrikaans, Arabic, Croatian, Dutch, German, Greek, Gujarati, Hebrew, Hindi, Hokkien, Indonesian, Japanese, Lao, Macedonian, Polish, Portuguese, Serbian, Serbo-Croatian, Sinhala, Taiwanese, Tamil, Vietnamese, and Unspecified.^fOther religion was Zoroastrianism.^gTwelve individuals identified their specific disabilities. Ten out of 12 (83%) included at least 1 neurodevelopmental/mental health condition, including attention-deficit/hyperactivity disorder, anxiety, autism spectrum disorder, bipolar disorder, depression, and/or unspecified psychiatric conditions. Physical disabilities included chronic pain, endometriosis, multiple sclerosis, and polycystic ovarian syndrome.

vs 2.2%, $P = .009$) or Canada (2.2% vs 0.2%, $P < .001$),⁴³ and affiliated with Judaism (5.3% vs 0.4%, $P < .001$) or no religion (63.6% vs 41.9%, $P < .001$).⁴⁶ Compared with an age-matched Australian population, respondents were more likely to be in a de facto relationship (19.8% vs 14.8%, $P = 0.029$),³⁷ and a primary caregiver for child(ren) (43% vs 35.1%, $P = .001$).³⁸ However, when separating primary caregiver for child(ren) by sex there was no significant difference (female caregivers: 44.3% vs 39.1%, $P = .119$).³⁸ Although there is inadequate population census data about sexual orientation, current estimates suggest that approximately 3.5% of the Australian adult population identify as a minority sexual orientation,³⁵ which indicates a possible overrepresentation in our cohort (11.2% vs 3.5%, $P < .001$). People assigned as male at birth (6.9% vs 49.4%, $P < .001$),³⁴ those who were divorced (3.0% vs 8.2%, $P = .004$),³⁶ people living in Queensland (7.5% vs 20.3%, $P < .001$),³⁹ those living in inner or outer regional areas (6.6% vs 25.9%, $P < .001$),⁴⁰ and those affiliated with Christianity (26.3% vs 47.3%, $P < .001$)⁴⁶ were underrepresented in our cohort compared with the Australian population. There was no significant difference in the proportion of people born overseas in our cohort versus the Australian population (23.7% vs 29.2%, $P = .064$); however, there were no respondents born in China or Philippines, which are the third and fifth most common countries of birth in Australia, respectively.⁴³ Furthermore, there were no respondents who used Punjabi, which is the 5th most common language other than English used in Australia. There were no respondents who identified as a sex or gender other than male or female, resided in the Northern Territory, resided remotely or very remotely, identified as Torres Strait Islander; or affiliated with Islam.

Further analysis was conducted within our data set comparing characteristics of respondents aged under 35 years old with those 35 years and over, excluding year of arrival and characteristics expected to change with age (relationship status and parental status). Compared with respondents aged 35 years and older, those under 35 were more likely to be male gender (11.9% vs 4.4%, $P = .032$), live in a major city (98.9% vs 89.6%, $P = .006$), use a language other than English (28.7% vs 12.5%, $P = .0018$), and identify as a minority sexual orientation (18.8% vs 5.9%, $P = .002$). Those under 35 years of age were less likely to be affiliated with a Christian religion (17.0% vs 32.3% $P = .008$).

In comparison with the 2017 census,⁸ there were no significant changes in relation to age or gender. There were significant changes in the professional profile of respondents. The accreditation status of the GC workforce changed, with a higher proportion of respondents self-reporting as being certified (from 88/263, 33.4% to 116/252, 46.0%; $P = .004$). There was also an increase in the proportion of respondents who reported working more than 1 job (from 52/239, 21.8% to 83/235, 35.3%, $P = .001$).

In Australasia, a range of areas of practice are recognized. Comparing characteristics of those in clinical practice with those who are not, the proportion of GCs who identified as heterosexual was higher in clinical practice (172/201, 87% vs 37/47, 79%, $P = .043$). Other relevant personal and professional characteristics were similar.

Workforce diversity and inclusion

Perceived workplace diversity

Respondents working in a clinical GC team were asked about whether they felt there was diverse representation within their team (Figure 1). Most respondents perceived that their team was representative in relation to parental status (119/155, 77%), age (112/155, 72%), and family structure (89/154, 57%). Conversely, most respondents did not agree that their GC team was representative in relation to gender identity (138/155, 89%), physical disability (132/155, 85%), language (116/155, 75%), neurodiversity (105/155, 68%), ethnicity (101/155, 65%), sexual orientation (96/155, 62%), and chronic illness (86/155, 56%). Approximately one-third of respondents were unsure whether their GC team was representative in relation to religion (57/155, 37%) and chronic illness (48/155, 31%).

Experiences of workplace diversity and inclusion

Respondents working in a GC team were also asked to comment on how the team currently supported their own diversity and inclusion. Ninety-one respondents provided examples of existing support. This included flexible working arrangements ($n = 43$), inclusive annual leave ($n = 32$), having a collaborative and inclusive team ($n = 17$), having a team supportive of professional development ($n = 10$), and visibility of diversity in the workplace ($n = 6$). Some respondents were unaware of any support ($n = 7$), felt their team was not diverse ($n = 5$), or felt that improvement was needed ($n = 3$).

Supporting workplace diversity and inclusion

Respondents were asked to comment on what could accomplish a more diverse and inclusive workplace. Forty-one respondents provided suggestions, including providing cultural and socially inclusive training for practicing GCs ($n = 12$), employing a diverse workforce ($n = 9$), creating accessible and inclusive work spaces ($n = 6$), allowing flexibility in work hours and locations ($n = 5$), making diversity visible ($n = 5$), providing funding ($n = 3$), engaging with community representatives ($n = 3$), focusing on First Nations visibility and inclusion ($n = 2$), and collecting data on workplace barriers to address them ($n = 2$).

Most respondents felt that they were able to obtain support to address these issues (126/174, 72%). Twenty-five respondents commented on barriers to obtaining support in relation to workplace diversity and inclusion. This included

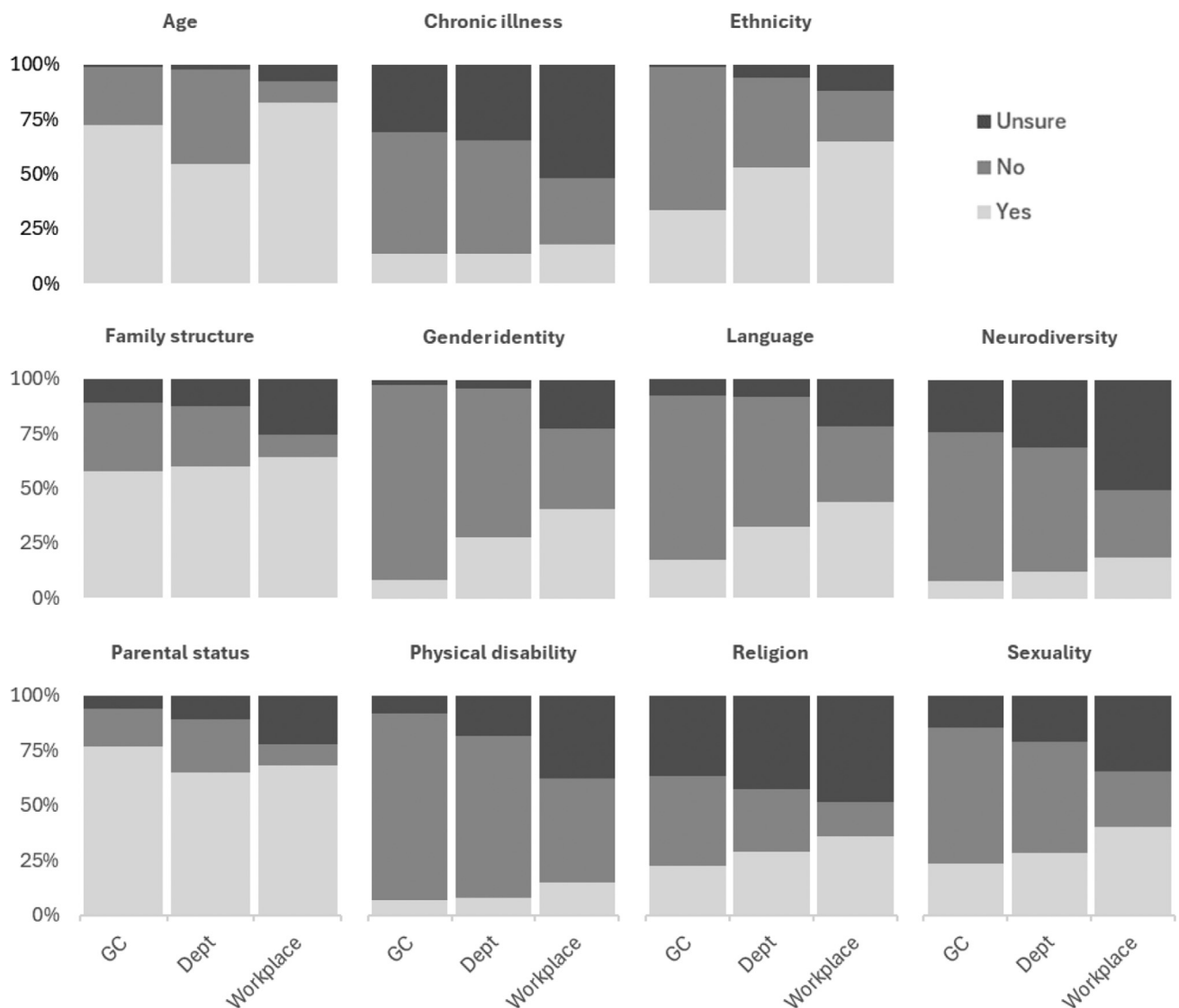


Figure 1 Perceived diversity of representation in genetic counseling teams (GC, $n = 155$), genetics departments (Dept, $n = 153$) and overall workplace (workplace, $n = 181$).

requiring support from colleagues and decision makers ($n = 11$), lack of resources ($n = 10$), navigating bureaucratic processes ($n = 3$), lacking confidence or feeling too junior to raise issues ($n = 2$), or employed on a temporary/honorary contract ($n = 2$).

Only 5 respondents reported that they required and requested accommodations for themselves in the workplace, with 3 requests granted. Requests primarily related to flexible work hours, working from home arrangements, and a personalized pathway for certification. Challenges included a slow process and experiences of issues being “normalized” or “minimized.”

Respondents were asked to comment on what their professional body (ASGC) and its DICE Working Group could do to promote a more diverse, equitable, and inclusive workforce. Sixty-two participants provided comments. They suggested that diversity should be promoted in the workforce ($n = 29$) through initiatives such as promoting the profession at high school level, directing promotion toward

minority groups, reducing course fees, and providing scholarships for minority groups. Other comments related to providing diversity and inclusion resources for the profession ($n = 19$), understanding and acknowledging workforce limitations ($n = 14$), promoting visibility of diversity and related issues ($n = 13$), improving access to general resources, such as professional body websites, webinars, and conferences ($n = 9$), targeting interventions at specific minority groups ($n = 9$), ensuring diversity on professional committees ($n = 5$), advocating on behalf of the workforce ($n = 4$), and improving accessibility of processes such as registration and certification ($n = 4$).

Inclusive care for clients

Experiences of providing inclusive care for clients

Respondents working in a GC team were asked to comment on how the team supported inclusion of clients.

Of 105 respondents who provided examples, most reported using interpreter services ($n = 68$) and diversity officers ($n = 53$). Many also reported that their team promoted visibility of diversity online via their email account or website ($n = 71$, by wearing items such as pins and lanyards ($n = 58$), or in their workplace through policy statements or posters in the reception area ($n = 21$). Respondents also gave other examples of inclusive practice, such as providing accessible clinic spaces (eg, disability parking or gender-neutral toilets) ($n = 32$), ensuring that appointments were accessible and flexible ($n = 17$), using a client-centered approach ($n = 10$), ensuring that written materials were inclusive ($n = 9$), and using visual aids in appointments ($n = 2$). Six respondents commented that they were unaware of any support.

Consistent with the open-text responses above, nearly 80% (153/194) of respondents working in clinical practice agreed that they had used multicultural services within their workplace. The most used services were interpreters (143/153, 94%), Aboriginal health units (64/153, 42%), and pastoral care (37/153, 24%). The most cited reasons for using these services were to provide language interpreting for clients (138/153, 90%), to assist in arranging appointments (93/153, 61%), and to support clients during consultations (88/153, 58%). Furthermore, 52% (96/184) of respondents collaborated with a community organization or member of a particular community group representing disability (68/96, 71%), First Nations (60/96, 63%), lesbian, gay, bisexual, transgender, queer (or questioning), intersex, and asexual (or ally) (43/96, 45%), ethnic (38/96, 40%), and religious (29/96, 30%) communities. Collaboration related to client information development (45/96, 47%), service-related projects (42/96, 44%), professional development (39/96, 41%), and research (35/96, 36%). Three respondents provided open-text responses to this question referring to GCs providing services for community groups ($n = 3$), collaborating to increase access to genetic services for the community ($n = 3$), or consultation about resource development ($n = 2$).

Sixteen respondents who indicated collaborations commented on challenges, citing not knowing how or with whom to collaborate ($n = 5$), lack of funding ($n = 3$), time and flexibility required ($n = 3$), difficulty engaging communities in genetics or sensitive topics, such as termination of pregnancy ($n = 3$), burden placed on community members, such as those with chronic illness ($n = 3$), and language barriers ($n = 2$). Those who did not collaborate primarily reported that there was no opportunity for them to do so (70/87, 81%). Some selected that they did not have capacity (18/87, 21%), it was someone else's responsibility (13/87, 15%), or that they were not interested (1/87, 1%). Three respondents provided comments, stating that they have not worked in service development or research ($n = 2$) or that public hospitals do not allow time for this activity ($n = 1$).

Supporting inclusive care for clients

When prompted with suggestions about what could help respondents to incorporate diversity, equity, and inclusion into their work, most selected specific tools and materials (122/192, 64%), training and professional development (112/192, 58%), more advocacy and public policies (105/192, 55%), and more funding to develop DICE programs (97/192, 51%).

Thirty-six respondents provided comments about how services could be made more accessible for clients. Suggestions included flexible appointments ($n = 9$), inclusive language in written resources ($n = 8$), visibility of diversity ($n = 8$), use of technology or visual aids in appointments ($n = 5$), using a client-centered approach ($n = 4$), accessible clinic spaces ($n = 4$), and more subsidy for testing and travel ($n = 2$). Respondents also suggested access to ongoing resources such as education ($n = 11$) and support services ($n = 7$). Finally, respondents commented on revising service and teaching policies ($n = 4$), employing diverse GCs ($n = 3$), and engaging with community ($n = 3$).

Most respondents felt that they were able to obtain support to address these issues (129/162, 80%). However, 15 commented on barriers to obtaining support in relation to inclusive clinical practice, such as requiring support from decision makers ($n = 4$), resistance from hospitals ($n = 3$), lack of resources, such as funding ($n = 4$), time ($n = 3$), and training ($n = 3$), and being unsure of how to make improvements or who could authorize change ($n = 2$).

Workforce capacity

Almost all respondents perceived that demand for GC services increased over the last 5 years (186/195, 95.3%) and will continue to do so over the next 5 years (200/202, 99.0%). Two-thirds of respondents perceived there is a critical shortage of GCs to meet the current (124/194, 63.9%) or future (128/202, 63.3%) demand.

In 2022, there were an estimated 630 individuals in Australasia holding a qualification in genetic counseling, of whom approximately 432 (68.6%) were working in clinical practice (Table 2). This proportion of those with a GC qualification in Australasia working in clinical practice has not changed significantly since the 2017 census (65.9% vs 64.1%, $P = .32$).⁸ Most respondents working in clinical practice were very satisfied or satisfied with their current job (152/178, 85%).

However, 9 respondents commented that they were satisfied with their line manager or employer but not with the wider organization or management. Factors impacting satisfaction for clinical GCs included support from employer or work environment ($n = 6$), type of work ($n = 4$), remuneration ($n = 5$), workload ($n = 5$), recognition of work ($n = 5$), autonomy ($n = 4$), access to sufficient resources and staff ($n = 3$), job security ($n = 3$), ability to

Table 2 Estimates of Australasian genetic counseling workforce capacity

Description/Justification	Data Point/Calculation	Data Source
Individuals with a genetic counseling qualification		
GC graduates from 2018 to 2022	30 graduates per year × 5 years = 150	Convenors of the 2 Master of Genetic Counseling courses serving Australia and New Zealand (personal communication)
GCs in Australasia who hold a qualification in genetic counseling	480 + 150 = 630	2017 census estimate ⁸ plus graduates since then
Total genetic counseling workforce across all roles		
Members of the Australasian Society of Genetic Counsellors (ASGC) when census was deployed	493	ASGC membership data from March 2023 (personal communication)
Survey respondents who reported having both a GC qualification AND ASGC membership	246/252 (97.6%)	2022 census data
GCs currently working in Australasia in a role related to genetic health (ie, not all those working in roles related to genetic health are ASGC members)	493/97.6% = 505	Calculation
Clinical genetic counseling workforce		
Survey respondents who reported having both a GC qualification AND working in clinical practice	201/235 (85.5%)	2022 census data
GCs in Australasia working in clinical practice (total number working multiplied by proportion of those working in clinical practice)	505 × 85.5% = 432	Calculation
Proportion of those with a GC qualification in Australasia working in clinical practice	2022: 432/630 (68.6%) ^a	2022 census data
Average (± SD) full-time equivalent reported by GCs working in clinical practice	0.8 ± 0.2	2022 census data
Estimated full-time equivalent GCs working in clinical practice in Australasia	432 × 0.8 = 346	Calculation

^aNo significant difference between 2017⁸ and 2022 census data (65.9%, 95% CI 60.2%-71.7% vs 95% CI 65.0%-72.2% from 2017 to 2022, $P = .432$).

work to full potential ($n = 3$), support for continuing professional development ($n = 2$), funding for service ($n = 2$), career progression opportunities ($n = 2$), and communication ($n = 2$).

Approximately 10% of respondents (17/176) were planning to retire in the next 10 years, and 5/176 (3%) were planning to leave the profession in the next 2 years. Comments from those planning to leave the profession related to low remuneration and lack of recognition.

Respondents working in clinical practice reported spending an average of $45.9 \pm 19.5\%$ of their time on clinical activities, ie, approximately 17.4 hours of a 38-hour work week. Remaining time was spent on other tasks, such as research ($24.2\% \pm 18.5\%$), administration ($16.6\% \pm 10.3\%$), management ($15.9\% \pm 16\%$), and other professional activities ($13.5\% \pm 12.3\%$). They reported spending an average of 4.4 ± 0.5 hours on clinical tasks per new patient referral, from preparation to follow-up, including appointments, and not over a defined period (Table 3).

Discussion

Supporting diversity and inclusion for both the workforce and clients is a key priority for the GC workforce in Australasia and internationally.^{5,17-19} This study provides baseline data regarding workforce diversity and inclusion in

Australasia. The study describes perceived representation in the GC workforce. It also provides novel insight into how inclusion may be put into practice for both the workforce and clients at individual, workplace, and workforce levels. Finally, the census provides updated data about the GC workforce capacity in Australasia.

Diversity and inclusion

Our cohort of the GC workforce lacked diversity across several characteristics, including sex, relationship status, caregiver status, location, country of birth, Aboriginal/Torres Strait Islander identity, language, and religion. Furthermore, a majority of our cohort perceived that their GC team was not representative of the general population in relation to gender identity, disability, language, ethnicity, and sexual orientation, regardless of actual representation. The high proportions of respondents using English, living in metropolitan regions, and residing in Victoria or New South Wales are expected. This reflects English language requirements for work and study in Australasia and locations of genetic services. However, lack of representation regarding other characteristics may be due to people in minoritized groups experiencing lack of awareness about the profession, financial barriers, additional burdens in attaining the necessary higher education, lack of diversity in higher

Table 3 Self-reported time spent on clinical tasks per client

Task	<i>n</i>	Average (min ± SD)
Preparation for new referral (triage, intake call, retrieving records, determining options, appointment booking, etc)	176	43 ± 32
First appointment (telehealth or face-to-face)	177	54 ± 22
First appointment follow-up (coordinating testing, completing forms, case notes and letters, referrals, psychosocial follow-up, etc)	175	50 ± 32
Preparation for Review/Results appointment (reviewing/interpreting results, reviewing records, etc)	174	30 ± 22
Review/Results appointment (telehealth or face-to-face)	174	39 ± 20
Further follow-up activities (case notes and letters, referrals, psychosocial follow-up, coordinate further testing/management, summary letters, etc)	176	49 ± 32
Total ^a		263 ± 27

^aTotal time spent per client was calculated based by summing the average time spent per client on each clinical task. This may be an overestimate for clients who do not require all clinical tasks.

education settings, and/or concerns that they will lack autonomy or experience discrimination in the workplace.^{2,4}

Key strategies to foster diversity and inclusion suggested by survey respondents related to promoting workforce diversity and a need for training opportunities about diversity and inclusion. These needs are not restricted to Australasia, and promoting GC workforce diversity is a key priority internationally.^{5,17-19} Furthermore, the National Human Genome Research Institute's Action Agenda highlights the need for diversity and inclusion education for the genetics workforce.¹⁹ It is important to note that education extends beyond awareness; it also involves understanding how to integrate cultural considerations into practice and how to address inherent biases of the workforce.⁴⁹

Making diversity visible was also identified as a key strategy in our study relating to inclusion in the workforce and for clients. Lack of visibility for minority groups may have negative impacts, such as ableism⁵⁰ and emotional, physical, and academic fatigue.⁵¹ It is important to promote visibility in a safe way, considering the personal autonomy, potential for discrimination, pressure to represent a whole community if personal diversity is visible, and the option of making inclusive values visible instead.^{50,51}

Health care providers and relevant organizations may foster inclusion for the workforce and for clients in several other ways. These may include promoting workforce diversity, shifting organizational culture, challenging power structures, assumptions, and stereotypes, and ensuring inclusive spaces and resources.^{16,52,53} Such strategies require proactive commitment from individuals, workplaces,

educational institutions, and professional bodies. Some strategies may target specific community groups, and some may consider intersectionality, diversity, and inclusion at a broader level. Strategies specific to the GC context based on our survey responses are summarized in Table 4. Of note, some participants suggested diversity and inclusion strategies that were reported as already in place by others. This may be due to workplace differences and considerations that need to be understood and addressed. Furthermore, approaches used to address workforce capacity may also provide opportunities to implement diversity and inclusion strategies.

Workforce capacity

The evidence base for both size of GC workforce and capacity of services to meet demand is highly variable across regions.^{20,23} The 2024 HGSA Clinical Genetic Services Framework provides a model, which includes data from this census, to calculate and articulate Australasian workforce gaps and service needs.⁵⁴

There has been a marked increase in full-time equivalent (FTE) GCs working in clinical practice in Australasia between 2017 and 2022 (estimated 220 vs 346). There are over 30 graduates per year from 2 courses currently offered in Australasia (personal communication), and there has been more funding in genomic health research over this period.⁵⁵ However, there are still not enough GCs working in clinical practice to meet demand in Australasia. Furthermore, 10% plan to retire in the next 10 years, and 3% plan to leave the profession in the next 2 years. The proportion of GCs who work in clinical practice has remained the same since 2017. The HGSA service level calculations for 2023 estimate a current demand for 418 FTE GCs working in clinical practice.⁵⁴ Our estimate of 346 FTE GCs currently working in clinical practice therefore suggests an estimated shortfall of 72 FTE GCs. This equates to 90 individual GCs if we adjust for the current average 0.8 FTE reported by our cohort. This shortfall is likely an underestimate as it assumes that all graduates will go on to work in clinical practice, and no one will leave the Australasian GC workforce. Service level calculations should also account for nonclinical responsibilities, such as management, certification, supervision, professional development, and research.

Workforce capacity is a complex issue and addressing it requires a multifaceted approach. To increase workforce capacity, education and training have been proposed for both the genetics and nongenetics workforce.^{8,56} Workforce development efforts could focus on graduate programs or supporting the one-third of individuals with a GC qualification who are not currently practicing clinically.⁸ However, there are limited full-time positions available for GCs in the public sector.²⁶ Addressing the shortfall in positions requires additional funding in both the public and private sectors. Neither private health insurers nor the Australian national insurance scheme (Medicare Benefits Schedule)

Table 4 Summary of suggestions to promote diversity and inclusion for genetic counseling workforce and clients

Suggestion	Professional Bodies	Workplace	Individual
Make overarching changes	<ul style="list-style-type: none"> • Advocate for diversity and inclusion on behalf of the profession • Allocate funding to diversity and inclusion related activities • Promote visibility of diversity and inclusion related issues • Target interventions at specific minority groups • Understand issues through data collection and consultation 	<ul style="list-style-type: none"> • Allocate funding for diversity and inclusion related activities • Collect data on workplace issues • Make diversity and inclusion more visible • Remove barriers for GCs attempting to obtain support for themselves or others • Revise service policies in relation to diversity and inclusion • Target interventions at specific minority groups 	<ul style="list-style-type: none"> • Make diversity and inclusion more visible
Promote a more diverse workforce	<ul style="list-style-type: none"> • Promote diversity in training programs through promotion of the profession at high school level, directing promotion toward minority groups, reducing course fees, and providing scholarships for minority groups • Ensure diversity on professional committees 	<ul style="list-style-type: none"> • Employ GCs from a diverse range of backgrounds 	N/A
Improve general accessibility for the workforce	<ul style="list-style-type: none"> • Improve access to general resources such as professional body websites, webinars, and conferences • Improve accessibility of processes such as registration and certification 	<ul style="list-style-type: none"> • Allow flexibility in work hours and locations • Create accessible and inclusive workspaces 	N/A
Provide diversity and inclusion resources	<ul style="list-style-type: none"> • Provide diversity and inclusion professional development • Provide diversity and inclusion resources • Revise teaching policies in relation to diversity and inclusion 	<ul style="list-style-type: none"> • Provide diversity and inclusion education opportunities for employees 	N/A
Promote inclusive practice for clients	<ul style="list-style-type: none"> • N/A 	<ul style="list-style-type: none"> • Make clinic spaces more accessible • Offer flexible appointments • Provide access to supports such as interpreters and community representatives • Provide more subsidy for testing and travel • Use inclusive language in written resources • Use technology or visual aids in appointments 	<ul style="list-style-type: none"> • Offer flexible appointments • Use a client-centered approach • Use inclusive language in written resources • Use technology or visual aids in appointments

reimburse these consultations. Relevant professional societies such as ASGC continue to advocate for this.

Other approaches may be used to support GCs to practice at the top of their scope. Although these approaches will not decrease the growing demand for GCs, they may enable limited GC capacity to be prioritized for clients with higher accessibility, psychosocial, and/or genetic needs. In our cohort, respondents spend an average of 17% of their time

on administrative tasks. The current rate of administrative staff in genetic services could be increased from 0.52 FTE⁵⁴ to 0.69 FTE per 1.0 clinical GC FTE in Australasia to reduce the average time spent by GCs on administration. Reallocating these tasks may increase individual capacity and reduce GC burnout.⁵⁷ Furthermore, certain models of “mainstreaming” may enable other health care providers to take greater responsibility for some of their patients’ genetic

care, including aspects of genetic counseling. Mainstreaming is relatively well progressed in reproductive and cancer genetics,⁵⁸⁻⁶⁰ whereas it is emerging in other areas of genetics.⁶¹ Finally, digital tools may be used to facilitate education and consent for some clients in some contexts.^{62,63}

Limitations and future research recommendations

Our data are reflective of the experiences and views of our respondents only. It may not reflect the views of the Australasian GC population. Furthermore, our analyses could not examine differences between countries of residence or compare New Zealand data with population data. As the workforce in each country increases, it may become possible for future research to understand these cohorts separately. Our study did not include demographic factors, such as socioeconomic status in early life, which may be included in future research. Furthermore, we were unable to explore intersectionality because of challenges in defining groups and limits in population data. This is an area that would benefit from future quantitative assessment. This publication only reports representation, experiences, and needs from the perspective of those who have a GC qualification and 2 current students. Therefore, our data may not reflect the views of individuals who face barriers that prevent them from entering the profession. Future research may aim to include more students along with people who have attempted to or wish to become a GC. The 2022 census includes data from individuals working in other professions related to clinical genetics (clinical geneticists, genetic pathologists, medical/clinical scientists, etc), allowing workforce issues to be examined across the Australasian genetic health profession more broadly in the future. It is also crucial to obtain the perspectives of other stakeholders, such as clients, consumer representatives, and support service providers.

Conclusion

Although the Australasian GC workforce has grown and matured over the last 5 years, it still does not have the capacity to meet current or future demand. Changes to education, training, and/or administrative support may enable the workforce to keep up with demand. Our findings also highlight a lack of actual and perceived diversity in the current GC workforce. The challenges identified in achieving diversity and inclusion for the GC profession and clients are not unique to genetic counseling, or to Australasia. Some of the strategies proposed by respondents are also of relevance internationally. Thoughtful change is needed at multiple levels: the health system (and in socialized medicine systems, the government), organizations (such as professional bodies, health care services, and genetic services), and individuals (including GCs). Our study provides a first step,

illuminating the changes needed in Australasia. We hope that our survey may be of use internationally, enabling other countries to understand these issues within their jurisdiction and supporting the international community in addressing these challenges.

Data Availability

Data are available in the results section of this paper.

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Ethics Declaration

This study was approved by the Human Research Ethics Committee of the University of Melbourne (HREC ID 2022-24482-30266-2).

Conflict of Interest

The authors declare no conflicts of interest.

Additional Information

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