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The experiences of UK-based genetic counsellors working in mainstream settings

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Most UK-based genetic counsellors (GCs) work within clinical genetics services; yet there is a small and expanding group of GCs working within other clinical specialties, termed "mainstream" GCs. To our knowledge there have been no projects to date examining the experiences of mainstream GCs working in the UK. The aim of this workforce evaluation was to explore the experiences of mainstream GCs. Online surveys were sent to mainstream GCs to obtain general demographic information and baseline data regarding experiences of working in these roles. Those who completed the surveys were then invited to take part in online focus groups. Data was transcribed and analysed using thematic analysis to draw out major themes that arose from the discussions. Major themes were found to be: "Benefits", "Challenges", "Career Progression" and "Support". Overall, participants expressed enjoyment of their roles and described key benefits of working in a clinical specialty, including autonomous working and developing expertise. Still, career progression was limited in many cases due to issues obtaining professional registration, lack of support, and unclear definition of the mainstream GC role. Findings are brought together as a list of suggestions to support this subset of the profession going forward. We hope these findings could be of utility to both employers and policymakers when advancing the national provision for mainstream genomic services.

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INTRODUCTION

At least 11 European countries have an established role for genetic counsellors (GCs), of which the UK has the largest established workforce, estimated to be 310 GCs [1]. UK-based GCs are expected to obtain voluntary professional registration via the Genetic Counsellor Registration Board (GCRB). Support is also provided by a UK professional body: The Association of Genetic Nurses and Counsellors (AGNC). The AGNC provides a proposed career structure for UK-based GCs, ranging from a pre-registration trainee GC, to a GC, to more senior roles of principal and consultant GC [2].

Most UK-based GCs work within clinical genetics services as part of the national health service (NHS); however, GCs are also permitted to work autonomously or as part of multidisciplinary and specialist teams throughout the NHS [1]. This appears to be similar to the situation in the rest of Europe where GCs are primarily reported to be based within clinical genetics services [1, 3].

A "mainstream" GC is defined as an individual based primarily in a speciality outside of clinical genetics services [4]. Mainstream GCs are sometimes referred to as "specialist" GCs due to working within specialist settings. The term mainstream GC will be used throughout this paper for clarity.

According to the most recent workforce survey by the AGNC in 2019, there were 13 GCs working within specialist settings, including cardiology, ophthalmology and cancer [5]. This figure may be an underestimate as only GCs who are AGNC members will have been invited to take part in their survey. As there have not been any workforce surveys undertaken in recent years, there is no accurate figure available as to how many mainstream GCs are currently working in the UK. Still, in 2022, with an upsurge in mainstream genetic testing started by the 100,000 Genomes project and propelled by the national Genomic Medicine Service, we can expect the demand for mainstream GCs to increase [6].

The important role that GCs can play within a specialist multidisciplinary team has long been recognised [4]. GCs are expertly trained to interpret complex genetic information and feedback to families and their clinical teams, shaping their ongoing clinical management whilst maintaining a supportive role [7]. A 2019 study by Sanderson et al. [8], interviewed healthcare professionals whose patients were recruited to the 100,000 Genomes Project. They found that non-genetic clinicians have concerns around a lack of genetic knowledge when consenting patients, and the time pressures of both performing consent and interpreting and feeding back complicated genetic results. The study highlighted the need for dedicated genetic support for specialist teams.

Still, there is currently a lack of published data looking into the experiences of mainstream GCs working within the UK. The following workforce evaluation aims to bring together and examine these collective experiences to aid understanding of this subset of the GC role.

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Table 1. Results from participant surveys.

Results from participant surveys	
Area of specialty	**Key statistics**
62% (8/13) work in cardiology	62% (8/13) have access to counselling supervision
31% (4/13) work in ophthalmology	46% (6/13) work alongside a clinical geneticist
8% (1/13) work in foetal medicine	75% (9/12) have dedicated administrative support
	50% (6/12) are registered with the GCRB or another board
	60% (6/10) are members of the AGNC

METHODS

Study design

The study was conducted in two parts. First, we invited mainstream GCs to take part in two online surveys. The first survey assessed demographic information in order to gather data about educational background, place of work, professional registration, administrative support and supervision. The survey contained open-ended questions and multiple choice questions. The second survey contained more open-ended questions and Likert scale questions addressing the challenges and benefits of participants' roles; how likely they were to stay in their roles, and if they liked or disliked their current role. Both surveys were created online using Google Forms with links to the surveys sent via email.

Surveys were used for a number of reasons. Firstly, to gather demographic data easily without taking up time in the focus groups to do this. Secondly, the survey results were used to formulate questions for the focus groups. Lastly, the anonymous nature of the surveys allowed the GCs who took part to be open and honest about their roles.

Upon completion of the surveys, all participants were invited to attend a virtual focus group. Focus groups were semi-structured with topics chosen beforehand, allowing participants to take the conversation where they wanted it to go. Thematic analysis was used to interpret the focus group data. We chose thematic analysis because we had subjective data, that we wanted to bring together into common themes to get an insider's perspective into their experiences [9, 10].

Participants

Invitations were sent to all known GCs who had the job title 'genetic counsellor' and fulfilled the criteria of:

- working in a clinical genetic counselling role in the UK
- working outside of a clinical genetics department
- working primarily with consultants who are not geneticists

The study was advertised through a regular online meeting: the specialist and mainstream GC journal club (see Appendix 1).

Procedures

The surveys were written by KM and EQ. They worked together to try to identify key questions and formulated two surveys to gather data. Three focus groups were conducted with three participants in each group. Overseeing each group was an interviewer (EQ) and notetaker (KM). The notetaker also facilitated by asking follow-up questions when appropriate. Focus groups were conducted via Microsoft Teams due to COVID-19 restrictions. The focus group format was chosen as it allowed interaction between participants to stimulate discussions and to hear about their views and experiences [11].

Ethics

The study followed the principles of the Declaration of Helsinki [12]. Ethical approval by the NHS Research Ethics Committee (REC) review for England was requested but deemed not necessary since the study participants were NHS staff members. Research and Development approval was confirmed to be not needed. The participants gave their verbal consent to participate in the focus groups after receiving written and verbal information about the study. The study was completely voluntary, and participants could withdraw at any time. Participants were informed that they could refuse to answer any questions, should they wish. All data was stored in secure cloud storage and only accessed by the project team. No identifiable information was used in this paper.

Data collection

All survey responses were collected between April and May 2021 and focus groups took place in June 2021. The interviews were recorded and transcribed using Microsoft Teams. The auto-generated transcripts were then viewed alongside the video recordings and any typographical errors were amended.

Data analysis

The focus group data was analysed using thematic analysis in order to elicit the participants' opinions and views. EQ and KM completed their analyses separately and then compared notes. The project team followed Braun & Clarke's six-phase guide [9]. The first step was to become familiar and immersed in the data. EQ and KM read and re-read the data and took initial notes. Following this, codes were generated. This was done by highlighting any ideas or feelings that seemed relevant or interesting and assigning labels that described them. The codes were then organised into themes. Themes were generated by looking at the codes and combining them into a broader idea that seemed to fit together under one topic. Themes were reviewed and, at this stage, EQ and KM compared their codes and themes. The themes were then combined, reviewed, and edited until we were left with four overarching themes. EQ and KM defined the titles and descriptions of the themes and drew a thematic map to illustrate relationships between themes.

Both authors are mainstream GCs, which may introduce bias into the paper. In order to reduce bias as much as possible, we did not participate in the focus groups. In addition, none of the authors' viewpoints, experiences or quotes are included in the paper. We also attempted to reduce bias by having both EQ and KM code and develop themes separately and then combine their analysis at the end.

Using a combination of anonymous surveys and focus groups helped to ensure participants were able to give truthful answers, leading to a reduction in measurement and respondent bias. This was especially important as many participants were known to the authors and to the other participants. Similarly, the survey helped form a topic guide for the focus groups that was relevant to the study population, not just based on our own experiences and viewpoints.

Results—Surveys

There were 13 responses to the first survey. Key results from the surveys are highlighted in Table 1. Years of experience as a mainstream GC ranged from less than one to ten plus years. All participants were female and worked in the NHS. The majority of participants worked full-time (84.6%) and in permanent positions (92.3%). Participants worked across a range of specialities: cardiology, foetal medicine and ophthalmology.

Eleven participants had completed an MSc in genetic/genomic counselling, one had done an MSc in Genomic Medicine, and one had participated in counselling and genomics workshops. None were registered nurses.

A minority of participants (39%) had a formal arrangement for clinical supervision, defined as a structured agreement established with a senior colleague to meet to review complex or challenging cases. Whereas the majority had access to counselling supervision (62%), a quarter (25%) of participants had no administrative support in their roles.

A third (33%) of participants were registered with the GCRB. Of the remaining participants, one was working towards registration, five were trying to get a sign-off mentor for registration and one was registered with another regulatory body.

There were 11 responses to the second survey. The majority of participants stated that they were happy in their roles (73%) and most felt

Table 2. Table of themes.

Benefits	Challenges	Career progression	Support
Autonomy	Isolation	Service development	Regional genetics services
Becoming an expert	Managing expectations	Specialising is the future	Multidisciplinary team
Teaching opportunities	Lack of understanding (team)	Limitations to career progression	
Continuity of care	Lack of understanding (manager)	Difficulties with GCRB registration	

supported by their managers and coworkers (73%). Still, eight (73%) GCs planned on leaving the role within 5 years or less.

Results—Focus Groups

Four major themes were identified: "Benefits", "Challenges", "Career Development" and "Support". A table of themes was created to summarise the themes and their subthemes (Table 2).

Benefits

This theme brings together all of the positive aspects mainstream GCs describe about their roles. Many participants spoke passionately about their enjoyment of this unique and challenging job.

> "[I] enjoy the autonomy… [you] can handle kind of everything and only get cardiologist or geneticist input where it's really, really needed… And I really love becoming kind of an expert… if you were doing half a dozen other things you can't really get 'in depth' with it."

In this statement, the participant describes how she enjoys the autonomous nature of the role, something that was highlighted by all participants. As she works in a specialist cardiac setting, like most participants she has developed an in-depth knowledge of the subject area, giving her a feeling of expertise.

Another unique benefit to mainstream GCs is being embedded within the patients' care. The following quote highlights the benefits of this, both to the professional and the patient. Not only are mainstream GCs able to see a patient throughout their care journey, the patient is given continuity of care whereby they can loop back into their dedicated genetics team at any life stage at which it is relevant.

> "I really like that you develop a longitudinal relationship with the families. You maybe aren't just seeing them when they're there for a genetic counselling consultation, but you kind of stay in touch with them 'cause you're embedded with their care team and that gives them a chance to come back to you with things that they maybe wouldn't have re-referred themselves to a department for."

Challenges

This theme reflects the more difficult aspects of the mainstream GC role. Frequently participants spoke about feelings of isolation within the role, particularly when working alone.

> "You're still slightly on the outskirts … I was working alone… I just wanted someone to bounce ideas off sometimes. You know, just have a chat with or you have a really difficult patient and you just want to talk to someone you know just vent about things"

Others spoke of a lack of engagement and understanding from their team members in terms of the psychosocial and ethical considerations in genetic testing.

> "We're presenting… the ethical dilemma and [the doctors are] asking: 'Oh, can we see the images of their eyes?' And I'm like, 'well, that's not the point of this case…we're talking about this dilemma that's happened'… And then it just becomes this conversation between all these doctors just talking about ... [what] the back of their retina looks like"

Many participants spoke of the challenge of having managers who don't fully understand their role.

> "My official manager is the lead genetic counsellor at the clinical genetics service, but she works in a different hospital and doesn't really have any idea what I do on a day-to-day basis and doesn't really know how to support me in growing as [a] genetic counsellor. And then my sort of day-to-day manager is a [non-genetic consultant] who also doesn't know very much about what being a GC is."

Similarly, participants described the struggle of having to advocate for themselves in a team where they may be the minority voice. This could lead to a battle of wills, in terms of managing both the clinicians' and the patients' expectations.

> "[The doctors] want to test immediately for it and…you sometimes feel like a parrot on repeat like 'no, no we can't do this. We can't do this.'… You don't have a team behind you…and as well as managing patient expectations because the cardiologist has said, 'yeah, we're definitely going to do a genetic test'."

Career progression

It was interesting to hear different perspectives on the career trajectory for mainstream GCs. Whilst a few participants had been able to progress in their roles, with one eventually being promoted to a consultant GC role; the majority felt working in a mainstream role was limiting their opportunities for career progression. In particular, barriers to obtaining GCRB registration were highlighted as significantly impacting career advancement.

> "I have thought about leaving my role. I wouldn't want to because I do love where I am and I love my job and the only thing that's made me think about leaving is the difficulties in [GCRB] registration and, linked to that, the kind of lack of potential progression because there's never been kind of a principal GC or a lead GC in the department so it does kind of make you think of it like 'I'm just going to be in this role for the rest of my life if I stay in this job.'"

Still, many participants expressed that they felt that specialisation will be the way forward for the genetic counselling profession in the future, and described many different ways in which they felt they could contribute to the development of their specialist services.

> "When I think about the future for me career-wise, I think about the future of that role. You know, things that I could build into the clinical and research program for the hospital where I'm already at. You know, expanding clinical offerings for other patient groups."

The time demands of obtaining an honorary contract and a mentor at a clinical genetics service were highlighted as particular challenges in terms of GCRB registration. The majority of participants were unable to find someone at a clinical genetics service to mentor them.

> "I understand that the registered counsellors, it's a sacrifice of their time as well to be a mentor. But, it felt like before we could even get to that barrier of giving up the time and the energy to commit to doing it, there was a whole separate process of grovelling to have the opportunity"

Table 3. Suggestions for employers of mainstream GCs.

Needs of a specialist genetic counsellor	Specific suggestions
Access to genetics expert	Clinical geneticist, senior genetic counsellor, clinical scientist
Counselling supervision	Group/individual supervision, within specialist team/outreach to genetics service
Managerial support	Has good understanding of role and is supportive of unique needs
Time to establish links	Opportunities for meetings, journal clubs with other genetic counsellors
GCRB registration	Access to a mentor, support from regional genetics services, time allocated in role
Support from team	Multidisciplinary meetings, time with clinicians to review cases
Administrative support	Dedicated secretary/admin assistant, genomics assistant/associate
Forum to review psychosocial/ethical issues	Attendance at national meetings (e.g. Genethics), forum for internal discussion

Support

Participants described the complex web of relationships they draw on as a support network. Relationships within the multidisciplinary team were primarily highlighted as strengths that supported their work.

> "I've just instituted 'Thursday Reflections' where we [the two mainstream GCs in the team] reflect on our cases of the week…we have MDTs on a Wednesday, so if we have any complex cases we just bring them up with the consultants"

All participants stated that they wanted to have established links with clinical genetics services. Some had good links, whereas others found their links were strained. We explored how these interactions have gone in the past.

> "The particular response [from the GC in a clinical genetics service] was really belittling because … I wasn't asking a basic question about how genetic testing works. So, I think there's this barrier to understanding what our job roles are and what our knowledge base is that has really limited my ability to communicate with counsellors outside of specialties."

Overall, the "support" theme demonstrates how essential relationships are to the work of a mainstream GC. Being based outside a clinical genetics department, forging new relationships both within and outside their teams was essential to ensure participants were supported in their work.

DISCUSSION

The aim of this study was to elicit the experiences of mainstream GCs working in the UK. The findings highlight the unique needs of mainstream GCs and allow us to put together a list of suggestions which can be easily utilised by current and future employers of mainstream GCs.

The project findings demonstrate that, whilst mainstream GC roles are extremely varied, there are commonalities in both the perceived benefits and challenges of the role. Mainstream GCs spoke passionately about their autonomous roles which allowed them to develop expertise in their specialist areas. We assert that mainstream GCs will be a valued resource in informing the mainstreaming of genomics in the NHS. Indeed, the AGNC have previously highlighted the essential role mainstream GCs will play in mainstreaming genomic medicine, by offering an expert voice within the MDT and ensuring that care is not only centred around the whole person but also the whole family [7]. Middleton and Patch [13] have also highlighted the role of GCs in providing education and mentoring of other professionals within the specialist MDT.

Isolation was identified as a major challenge for mainstream GCs. Four participants were the sole GC within their team and all other participants worked with a small number of GCs (between one and three co-workers). To combat isolation, we have suggested that employers allow mainstream GCs time to establish links with other GCs to form a support network outside of their immediate team. An example would be Specialist & Mainstream Genetic Counsellors Journal Club (Appendix 1)—an online group which meets once a month and brings together mainstream GCs working across multiple sites for the purposes of support and learning.

Similarly, some participants spoke of a disjointed relationship with clinical genetics departments. The AGNC suggest that mainstream GCs "may wish to retain formal links with their consultant genetic counsellor colleagues for line-management, mentorship and counselling supervision" ([4], p5). However, findings from this evaluation suggest that it may not be easy or indeed feasible to establish such links, particularly at a time when departments are stretched. The importance of access to a clinical geneticist and counselling supervision is highlighted in our suggestions - employers should ensure that these links are formally in place so that mainstream GCs are appropriately supported in their roles.

The mainstream GC role is poorly defined and lacks national structure or guidance. Skirton et al. [14] found that there is a general consensus throughout Europe of the role of the GC and that it would be appropriate for GCs to work within specialist teams. However, many participants in this study spoke of lack of understanding of their role, either by their direct line manager or colleagues. Not only did this lead them to feel unsupported, but it also culminated in situations where mainstream GCs were asked to do tasks that they felt were inappropriate. Through describing the experiences of mainstream GCs, we hope to ensure that supporting and promoting the work of mainstream GCs is included in the national mainstreaming agenda.

Whilst all participants enjoyed their roles, many stated concerns regarding the lack of career progression. Not only is there no defined career structure for mainstream GCs, but many participants found they were unable to obtain GCRB registration, which is essential for career progression. Whilst 33% of participants were GCRB registered, all other participants wanted to become registered but had been unable to do so. Key barriers were finding a mentor and the greater time burden for mainstream GCs who are required to take on an extra caseload, on top of their full-time job. We have suggested that employers provide support for GCRB registration, but it is also essential that the GCRB and clinical genetics services are supportive of the needs of mainstream GCs in obtaining registration. Moreover, the majority of GCs we interviewed were thinking of leaving their role in the next five years or less. This demonstrates the high rate of turnover in mainstream GC roles. We hope the outcomes of this project and the tailored suggestion list (Table 3) for employers can address this high rate of turnover.

It is important to note that the findings of this study are based on the UK experience and so may not be directly comparable to the GC workforce in other European countries. Still, we believe the suggestions (Table 3) are likely to be applicable to our European colleagues, given that there are many commonalities to the GC role across Europe [3].

This study had a small sample size and results cannot be extrapolated to the experiences of all mainstream GCs working in the UK. We do not know the total number of GCs working in such positions; it is likely to be low currently, but expected to grow due to the roll-out of the national genomic medicine alliance and mainstreaming genomics initiative in the UK. We found that the roles of mainstream GCs are extremely varied and so we cannot present a unified picture, but more a general overview of the collective experiences in this unique role so far.

To our knowledge, there are no previously published papers on the experiences of mainstream GCs working in the UK. This project aims to provide a snapshot about the experiences of mainstream GCs to increase understanding of the role. An interesting avenue for further study would be to examine the experiences of GCs working in clinical genetics services and compare these findings with the experiences of mainstream GCs. A next step for this study would be to look at patient experiences when they have seen mainstream GCs.

We hope that provision of a suggestions list for current and future employers will ensure that the career path of mainstream GCs continues to flourish. This project highlights the promise of such a career path, and we hope it will encourage future GCs to work in a mainstream setting.

DATA AVAILABILITY

Full transcripts and survey responses available upon request by contacting the corresponding author.

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AUTHOR CONTRIBUTIONS

EQ and KM worked together to design the project including questionnaire and discussion guides for the focus groups. EQ was the interviewer and KM was the notetaker in the focus groups. EQ and KM both analysed the transcripts and performed thematic analysis. EQ and KM wrote the paper together.

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No financial assistance was received in support of this study.

COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

Correspondence and requests for materials should be addressed to Ellie Quinn.

APPENDIX 1

The Mainstream & Specialist Genetic Counsellor Journal Club was set up in October 2020. It is a virtual monthly journal club for any genetic counsellor in the UK that works in a mainstream GC setting or in an isolated role.