The Department of Health-supported genetic counsellor training post scheme in England: a unique initiative?

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Abstract Although the professional title ‘genetic counsellor’ has wide international recognition, formal courses or training programmes in genetic counselling exist in only a small number of countries. In 2002, voluntary registration of genetic counsellors in the UK began under the auspices of the Genetic Counsellor Registration Board. Practitioners are eligible for registration after 2 years of genetic counselling practice and prior attainment of either a nursing or midwifery qualification with relevant Bachelor's degree or a Master's degree in genetic counselling. After a government commitment to increase the genetic counsellor workforce, the national professional organisation for genetic counsellors obtained government funding to expand training capacity for genetic counsellors through a training scheme. The Genetic Counsellor Training Post Scheme was designed to

ensure that both appropriately qualified nurses and Master's level genetic counselling graduates were offered the opportunity to undertake a 2-year training period prior to registration. The scheme has proved highly successful. Of 43 trainees appointed, 42 went on to work as genetic counsellors, and 36 have already gained their professional registration. Details of this unique scheme including trainee outcomes and experiences are presented. This type of scheme may be appropriate for the development of the genetic counselling profession in other countries.

Keywords Genetic counsellor · Health professions · Professional practice · Training · Education

Introduction

Genetic counselling in the UK was first established in 1946 (Harper 1993). Clinical genetics services are now well established and delivered by the National Health Service (NHS) through specialist regional genetics centres. Each centre employs a multidisciplinary team involving doctors (clinical geneticists), genetic counsellors, administrative staff and scientists and covers a population of between three and five million people (Donnai 2002; Kerr 2011). The clinical component of the service is an outpatient-based specialty although patients are also seen on wards, in other locations including general practice and in the family home (Temple and Westwood 2006). Increasingly, some subspecialty services are provided in other clinics such as cardiology or oncology, but usually with shared responsibility with clinical genetics (Griffith et al. 2009).

Although the professional title ‘genetic counsellor’ is recognised internationally, formal courses in genetic counselling are not available in every country (Begleiter 2002; Sahhar et

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al. 2005). Prior to the 1990s, UK genetic counsellors were either ‘genetic nurses’ or ‘genetic social workers’, but formal training with a Master’s Degree in genetic counselling was established in 1992 at the University of Manchester and then in 2000 at Cardiff University (Kerzin-Storarr et al. 2002). This shift was reflected in the change of professional title for non-medically qualified genetic counsellors from ‘genetic nurse’ or ‘genetic associate’ to ‘genetic counsellor’, with the establishment of the Genetic Counsellor Registration Board (GCRB) in 2001 (Skirton et al. 2003).

Voluntary registration of genetic counsellors in the UK began in 2002 under the auspices of the GCRB. Trainee genetic counsellors working towards registration need to fulfil at least one of the following sets of ‘entry-level’ criteria (a or b) on obtaining a training post:

- (a) Attainment of a GCRB-accredited Master of Science (MSc) degree in genetic counselling, to include a substantial clinical and experiential component and basic training in counselling skills of at least 90 guided learning hours.
- (b) Attainment of a first or Master’s degree *and* a professional qualification as a registered nurse or midwife (with maintenance of current professional registration) *and*
 - Previous experience as a senior registered practitioner
 - Completion of an accredited genetics course of no less than 30-hours duration
 - Training in counselling skills of at least 90 guided learning hours

A training period of at least 2 years, full time (or part-time equivalent), is necessary prior to becoming eligible to apply for registration. Training must take place in a centre meeting the criteria set by the GCRB as a suitable training environment, with a named registered genetic counsellor acting as a training supervisor/mentor (GCRB 2012; Skirton et al. 2003). Assessment for admission to the register is based upon the applicant providing a portfolio of evidence demonstrating that he/she has attained the core competencies related to the full spectrum of genetic counselling. The competency framework was devised to allow a diversity of applicants’ backgrounds whilst ensuring standards required for autonomous professionals. Genetic counsellors have to renew their registration with the GCRB every 5 years, which requires the demonstration of continuing professional development and evidence that the practitioner is upholding the standards of practice.

Although the current registration system for genetic counsellors is voluntary, the UK Health Professions Council made a recommendation to the government in 2009 that the profession be statutorily regulated. The current UK government proposes a form of regulation involving quality assurance of voluntary registers, and this is currently under consideration.

Background to the genetic counsellor training post scheme in England

In 2003, a Government White Paper on genetics stimulated the expansion of specialist genetic services in the UK (Department of Health 2003). The White Paper contained a commitment to enlarge the genetic counsellor workforce to help address the increased pressure on genetic services. At that time, most UK genetic counsellors had a background in nursing, but an increasing proportion had an MSc in genetic counselling with no prior professional background. The diversity within the profession was considered to be a strength within genetics teams, and this was reflected in the design of the registration system in ensuring that people from a wide range of backgrounds were eligible to undertake the 2-year pre-registration training period. However, there was a danger that the need to leave salaried posts to undertake genetic counsellor training would act as a disincentive to qualified nurses and midwives joining the profession.

In 2002, the professional organisation for genetic counsellors in the UK, the Association of Genetic Nurses and Counsellors (AGNC), prepared a proposal to expand training capacity for genetic counsellors through a centrally funded training post (GCTP) scheme. The Department of Health (DH) granted funding for up to 50 posts, with financial support for the trainee’s salary and educational allowance together with a stipend to the host department. Each full-time post was for 27 months (or part-time equivalent). On completing training, the post holder was expected to be ready to apply for registration.

Approval of training centres

A key part of the scheme was placement of trainees in approved genetic counsellor training centres. All regional genetic centres in England¹ were invited to apply for approval and were assessed using the following criteria:

- A multidisciplinary approach to patient care
- A supervised genetic counsellor clinical caseload
- Clinical case meetings
- Availability of a named registered genetic counsellor to act as a training supervisor/mentor
- Established links with departments related to clinical genetics, including laboratories and other related clinical specialities
- Clinical and counselling supervision
- Opportunities for participation in clinical audit and research

¹ The Department of Health has a remit to administer services for England only. Scotland, Wales and Northern Ireland have their own devolved health departments.

- Access to educational opportunities through departmental seminars, study days and journal clubs with clinical application
- Learning resources, including appropriate IT facilities and library resources
- A minimum of three genetic counsellors (and at least 75 % of the total number in post) who were either registered or eligible for registration

A GCTP panel of three senior genetic counsellors with experience in practice, education and training and an experienced clinical geneticist reviewed all applications from potential training centres. Of 18 centres that applied, 17 were approved.

The scheme in action

Approved training centres were allocated funding for between one to four posts over the course of the scheme. A total of 43 trainees were appointed in the first two phases of the scheme. Appointment to the training posts was very competitive, with up to 70 applications received after advertisements for individual posts. This resulted in the GCTP attracting highly able and committed individuals into the profession. The majority of the trainees (86 %) trained in a full-time capacity. Three trainees were appointed on a part-time basis, with another three trainees commencing full-time training but changing to part time due to altered personal circumstances. Four trainees divided their training between two approved centres that were in geographical proximity to each other.

- *Learning contracts*

On appointment, the trainee and their mentor were required to draw up a personal learning contract to form the basis for planned provision of training opportunities. Learning contracts were required to reflect the trainee's previous qualifications and experience and to address fulfilling the competencies required for registration. An abbreviated example appears in Table 1.

- *Monitoring and evaluation of the scheme*

The scheme was monitored by the GCTP panel to ensure that each centre met its training obligations to the trainee and to determine continued approved status for the centre. The purpose of this evaluation exercise was to ensure that the scheme was meeting its aims. The panel was not charged to specifically assess individual trainee's professional competencies; trainees would instead be assessed through their developing portfolio for registration and through educational programmes completed during the training period.

Each centre was expected to:

1. Submit a learning contract within 1 month of the trainee taking up his/her post
2. Submit contract evaluation forms to the panel at 6, 12, 18 and 24 months together with a report of financial expenditure
3. Support the trainee and mentor to attend meetings organised by the panel

- *Joint-funded extension to the scheme*

In October 2009, the GCTP panel obtained DH funding for a third phase of the scheme, which will enable the White Paper commitment of 50 new genetic counsellors to be realised. In this third phase, the DH agreed to part-fund ten training posts by providing 50 % of the trainee's salary and on costs, as well as providing generous funding for an educational allowance and a training centre stipend. Seven centres were able to provide local part-funding for at least one trainee, and nine appointments were made. All trainees are currently undergoing their training.

Results

- *Trainee backgrounds*

One of the primary aims of the scheme, to ensure a diversity of backgrounds amongst the genetic counsellor workforce, was achieved. Around a third of trainees (37 %, $n=16$) had a professional background in the health or social services, mainly in nursing. Four of these trainees had also completed an MSc in genetic counselling. Half the trainees (51 %, $n=22$) had a scientific background and an MSc in genetic counselling, while the remaining five had neither a health professional background nor a genetic counselling MSc, but were graduates who used their training post to obtain a Master's degree in genetic counselling.

- *Post-training outcomes*

The vast majority of the 43 trainees (41 out of 43, 95 %) now hold a substantive genetic counselling post in a regional genetics centre. About two thirds of these (26 out of 41, 63 %) obtained a post in the centre in which they trained, with the remainder moving to practice in a different centre. One past trainee recently left her genetic counselling post after 5 years for family reasons, and another failed to complete genetic counselling training, returning to nursing practice.

Just five trainees did not obtain a genetic counsellor post immediately on completion of their training, and three of these did so within 7 months of completion. One had a voluntary career break for family reasons before gaining a genetic counselling post 1 year later. The remaining trainee completed training and left for 5 years before returning to re-commence her genetic counselling career.

Table 1 Genetic Counsellor Training Post Scheme: sample (abbreviated) learning contract

Name of Trainee:		Date started in training post:		This learning contract to be reviewed on: (date)	
Competence	Overall learning need	Strategy 0–6 months	Assessment	Strategy 6–12 months	Assessment
Elicit and interpret relevant medical, family and psychosocial history	Learn to draw accurate family tree	Read chapters on drawing family tree	Accurate family tree in patient notes—achieved		
	Become competent in obtaining and recording relevant history	Practice drawing own tree	Assessed by mentor observation		
	Become competent in making a genetic risk assessment	Observe mentor 15 cases			
		Take family tree under observation 10 cases			
Convey clinical and genetic information to clients appropriate to their individual needs.	Develop competence in explaining genetic information to clients	Undertake genetics short course	Assessed by mentor observation and reading of patient post clinic letters		
	Demonstrate cultural sensitivity when providing information	Observe variety of cases with different practitioners in clinical setting			
	Provide information relevant to client's understanding, language and circumstances.	Identify useful teaching tools for own use in clinic			
Competence	Overall learning need	Strategy 12–18 months	Assessment	Strategy 18–24 months	Assessment
Elicit and interpret relevant medical, family and psychosocial history	Learn to draw accurate family tree				
	Become competent in obtaining and recording relevant history				
	Become competent in making a genetic risk assessment				
Convey clinical and genetic information to clients appropriate to their individual needs.	Develop competence in explaining genetic information to clients				
	Demonstrate cultural sensitivity when providing information				
	Provide information relevant to client's understanding, language and circumstances.				

Of the 41 former trainees currently in a genetic counsellor post, 36 (88 %) are now registered genetic counsellors, with the remaining five intending to apply for registration as soon as they are eligible.

- Trainees' experiences of the GCTP scheme*

Past trainees recently completed a questionnaire about their post-training career paths and their experiences of the GCTP scheme. The vast majority of comments about the scheme and its contribution to the trainee's subsequent career were positive. A

number of trainees commented about the confidence they had gained through their posts:

"I feel that my trainee post gave me a really solid grounding in the profession and has given me a confidence and a breadth of practice which I see lacking in some of my colleagues (who did not have a training post)."

"The training post really did set me up ideally to pursue my career in a more confident manner as it

gave me the experience and structure which 'till today has served me well. I would strongly encourage the AGNC and GCRB to make this a more permanent and mandatory route to enter the profession post-MSc qualification. It is a unique training scheme which needs to be supported and preserved."

The opportunity to develop as a professional with structured training goals was thought to be particularly valuable:

"I cherish the precious training that the traineeship enabled me to get. It was a privilege and I made good use of it, accomplishing all those objectives that were set down and that provided me with a solid practice background."

In addition, the availability of funding for continuing education was appreciated:

"The time, support and financial assistance available during my training post provided an excellent basis for my work as a genetic counsellor after training. I particularly valued the opportunity, as a trainee, to attend a variety of courses, conferences, observations of other clinics etc. This grounding gave me exposure to the work of many organisations....and experiences....which have enabled more informed genetic counselling and information provision for my patients. I sincerely hope such excellent training opportunities can be provided for future trainees."

However, two former trainees commented on significant negative experiences of training, although both reported being settled and successful in their current posts.

"It was always a struggle to get cases...the post was not integrated into the department."

"My experience of the Trainee Post was far from pleasant and almost made me decide to end the career I had worked so hard for."

The GCTP panel provided support and guidance to trainees and training centres in the small number of cases where difficulties arose. This involved occasional telephone and email contact with trainees and mentors. Often, the panel were able to make suggestions about the structure of mentoring arrangements that resulted in the resolution of a perceived difficulty. In one case, face-to-face contact with both mentor and trainee was offered, accepted and perceived as providing a useful way forward. Although the amount of support required from the panel was minimal, many mentors and trainees perceived the availability of a 'neutral' panel to be important. Overall, the generally uncomplicated operation of the scheme was felt to have justified the manner of its introduction and practice, which involved the support of clinical geneticists and genetic counsellors.

Discussion

As recognised in the 2003 White Paper, genetic counsellors are emerging as a defined professional group integral to the multi-disciplinary specialist clinical genetics service in the UK. The GCTP scheme has played an important role in raising the profile and skill potential of genetic counsellors amongst medical and other colleagues working in clinical genetics. When the scheme was announced and regional genetic services were invited to apply for approval as a genetic counsellor training centre, there was overwhelming interest from both lead clinical geneticists and genetic counsellors. Many commented that the application and interview process raised their awareness of developments in the genetic counsellor profession. Since then, many departments have fed back on the benefits to the service of having genetic counsellor trainees.

UK genetic counsellor professional registration is based on the principle that in addition to prior academic and vocational qualifications, registered genetic counsellors need a 2-year training period to become appropriately competent. This is reflected in the career structure for genetic counsellors, developed by the AGNC in 2005 and currently being updated (Longmuir 2011, personal communication), which is mapped to NHS pay scales with progression from trainee level genetic counsellor to registered genetic counsellor through to more senior positions. The GCTP scheme, by providing the structure and funding for training posts, has helped to embed a career structure for genetic counsellors in the NHS.

The inclusive nature of the UK genetic counsellor registration scheme has enabled health professionals from diverse backgrounds to enter the profession. Historically in the UK, nurses working in the NHS were employed to work with clinical geneticists to provide genetic counselling services before the MSc genetic counselling training programmes were established. The profession has worked hard to avoid a split between practitioners with a nursing background and those with an MSc genetic counselling background with some having both qualifications. The motivation for maintaining a common genetic counsellor profession developed from close working relationships between early entrants to the profession in the UK who recognised the need to ensure high levels of professional competency to meet the expanding scope of practice for non-medical genetic counsellors, while also valuing the range of skills and experience of a diverse profession. The single registration mechanism, which requires all new genetic counsellors to spend 2 years working in practice (regardless of their previous background) before being eligible to apply for registration, has enabled new entrants to gain comparable competencies. From the outset, the 'entry requirements' for registration were devised specifically to avoid any 'split' between practitioners from differing backgrounds. Such a commitment to a single registration process has been consistently supported by the UK genetic counselling profession and is seen as a benefit to the provision of a comprehensive clinical service. The availability of

designated training posts as provided by the GCTP scheme has reinforced the ‘dual entry’ approach to the profession in the UK.

The GCTP panel, the AGNC Committee and the GCRB remain committed to the continuation of structured training posts and approval of training centres. Reports of the scheme have been presented to overseas audiences (Kerzin-Storarr et al. 2006; Barnes et al. 2007), generating interest from international colleagues about this unique model of a national scheme that provides 2-year post-qualification clinical training posts for genetic counsellors.

The most important outcome of the training post scheme is the benefit to patients and families. A trained genetic counsellor workforce means shorter waiting times for patients (who would otherwise join the queue for appointments in the limited number of consultant clinical geneticist clinics) and access to skilled counselling to facilitate decision making and adjustment to genetic diagnoses and testing.

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Conflict of interest The authors declare that they have no conflict of interest.

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