

# **STANDARDS OF PRACTICE FOR GENETIC COUNSELLORS**

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## INTRODUCTION

Qualified Genetic Counsellors have a MSc (Med) degree in Genetic Counselling and complete 2 years of internship and are registered with the Health Professions Council of South Africa (HPCSA) as independent practitioners. This is a requirement for practice. Genetic Counsellors fall into the category “Medical Scientists” under the Medical and Dental Board. The scope of the profession was defined in 2009 (Regulations defining the scope of the profession of medical science (R. 579) Government Gazette No. 32244, 22 May 2009) and this definition outlines the acts pertaining to medical scientists, which “shall be performed as an auxiliary and supporting service to medicine”. These include:

*“the development, evaluation and practice of scientific procedures, involving humans, which will lead to or impact on the treatment, diagnosis and counselling of humans (in the case of genetic counsellors) and, where appropriate, interpretation, quality management, patient genetic counselling and consultation with other registered and appropriately qualified health practitioners”*

This scope of practice is not intended to be considered inclusive of all practices or exclusive of practices that might achieve the same results. It is subject to the regulations of the local, state and national government of the country. Genetic counselling is a dynamic profession; therefore this statement will be reviewed periodically and revised as necessary, by the Genetic Counsellors-South Africa organisation, to maintain consistency with current practice.

## SCOPE OF PRACTICE FOR GENETIC COUNSELLORS

Genetic counsellors are health professionals, with specialized education, training and experience in medical genetics and counselling, who help people understand and adapt to the implications of the genetic contributions to disease (NSGC, 2006).

Genetic counsellors practice client-centered and non-directive counselling based on the belief that individuals have a right to: be informed of their genetic risks and reproductive options; access to psychosocial support during counselling sessions and the decision-making process; help with coping with the implications of their choices. They provide genetic counselling in accordance with their professional ethics and values, in various health settings.

Genetic counsellors work as independent professional practitioners with a unique knowledge base and set of skills and are not supervised in their practice, but work in consultation with a medical practitioner. As with all medical scientists, genetic counsellors perform an auxiliary and supporting service to medicine (Government Notice No. R.579, 22 May 2009) and do not diagnose nor treat patients for a medical condition. Genetic counsellors are part of the multidisciplinary health care team and work with medical practitioners and other health care professionals to provide the best care for patients and their families.

The scope of practice of genetic counsellors therefore includes:

1. Providing genetic counselling to anyone who is concerned about or referred as a result of the presence of a genetic disorder/s in him or herself or in the family
2. Collecting and interpreting comprehensive patient information, including medical, genetic and psychosocial family histories
3. Making appropriate and accurate genetic risk assessments, offering options for dealing with these risks and referrals to other agencies, as appropriate
4. Educating regarding the medical, genetic and scientific aspects of the condition/s and the associated risks
5. Using therapeutic short term counselling and communication skills to address the psychosocial needs of patients and their families and to assist them in making the best possible adjustment to the disorder
6. Requesting appropriate genetic tests, as indicated, in association/consultation with a medical practitioner
7. Liaising, in the form of consultations, discussions, written reports and referrals, with other healthcare professionals to provide optimum services
8. Planning, organizing and delivering professional and public education in genetic healthcare
9. Serving as a genetic health care resource for professionals and the general public
10. Participating in research in the field of genetic counselling, where possible

(Adapted from the Genetic Counsellors in the UK document 2007, the ABGC document 2007, and Kromberg et al, 2009, Extract from the Minutes 12 May 2010, Rules of conduct)

# COMPETENCIES

## A. Discipline Specific Knowledge (Genetic, Scientific, Medical and Counselling knowledge)

- Can describe and apply theoretical knowledge regarding epidemiology, aetiology, medical management, risks, and special investigations
- Can interpret genetic data
- Discuss current and developing technologies in all areas of medical genetics

## B. Communication Skills

- Can communicate effectively during genetic counselling sessions with patients and families from a variety of educational, socio-economic, ethnocultural, religious and historical backgrounds, taking into account traditions, health beliefs, lifestyles and values by
  - . Setting an agenda
  - . Obtaining an appropriate and inclusive family history
  - . Eliciting a social and psychosocial history
  - . Conveying genetic, medical, and technical information
  - . Facilitating the informed-consent process
- Can document and present case information clearly and concisely
- Can plan, organize, and conduct public and professional awareness and education programs

## C. Critical-Thinking Skills

- Can apply critical thinking during case preparation by
  - . Identifying relevant resources and applying them appropriately
  - . Conducting a critical and meaningful review of the literature
- In Genetic Counselling sessions, can
  - . Assess and calculate genetic and teratogenic risks
  - . Evaluate a social and psychosocial history
  - . Analyse and interpret medical, genetic, and family data
  - . Assess client understanding and response to information and its implications to modify a counselling session as needed
- In case documentation and follow-up, can
  - . Identify, synthesize, organize and summarize pertinent medical and genetic information, and manage case
  - . Assess client's understanding and needs for resources/services

## D. Interpersonal, Counselling and Psychosocial Assessment Skills

- In Genetic Counselling sessions, can
  - . Establish rapport and interact with patients and families

- Assess patients' and families' emotional needs, identify major concerns and respond to emerging issues
  - Provide short-term, client-centered counselling and psychosocial support
  - Manage patients and their families with empathy and cultural sensitivity
  - Reflect on how cases are handled and practice self-awareness
- In interpersonal relationships, can
  - establish and maintain inter-and intradisciplinary professional relationships
  - behave professionally and understand the roles of other professionals

### **E. Professional Ethics and Values**

- Can act in accordance with the ethical, legal, and philosophical principles and values of the profession; can recognize and respond to ethical and moral dilemmas arising in practice
- Can advocate for patients, recognize own limitations in knowledge and capabilities and seek consultation or refer and can show initiative for continued professional growth

### **F. Computer Literacy**

- Can demonstrate competency in computer literacy and make use of word processing, spreadsheet and database software to retrieve patient, test and procedure data, produce reports and maintain records.
- Can search, collect, organize and interpret information from different databases and sources.

### **G. Research Competency**

- Can define a problem, formulate a hypothesis, design and conduct a research project that will lead to meaningful results, and can write up a research report
- Can critically evaluate scientific literature

## CONTINUING PROFESSIONAL DEVELOPMENT AND SUPERVISION

Registered Genetic Counsellors are recommended to keep a record of Continuous Professional Development according to the HPCSA regulations (CPD guidelines available at: [http://www.hpcsa.co.za/downloads/cpd/activities\\_2011/guidelines\\_2011.pdf](http://www.hpcsa.co.za/downloads/cpd/activities_2011/guidelines_2011.pdf)). Periodic audits are conducted by the HPCSA.

Genetic Counsellors should attempt to ensure appropriate counselling supervision\*. In line with the UK recommendations (AGNC Supervision Working Group 2007) a genetic counsellor should have at least one hour one-to-one supervision or two hours of group supervision involving 4 members or less, a month, with appropriately trained supervisor #.

**\* Definition of Genetic Counselling Supervision - (AGNC Supervision Working Group 2007)**

*Genetic counselling supervision is a formal and contractual arrangement, whereby genetic counsellors meet with a suitably trained and experienced supervisor to engage in purposeful, guided reflection of their work. Focusing on the dynamics between client and genetic counsellor, the aim of this process is to explore the interaction between the counsellor and client, and the impact of external factors on this, enabling counsellors to learn from experience, improve their practice and maintain competence. The overall intention is to enhance the quality and safety of client care and to promote the ongoing professional development of the counsellor.*

**# Definition of appropriately trained supervisor - (AGNC Supervision Working Group 2007)**

*An appropriately trained supervisor refers to a person trained specifically in supervision (psychological skills i.e. a psychologist, social worker, or genetic counsellor). The supervisor should be external to the department and the internal line management structure.*

## RECIPROCITY

### **Applications from foreign individuals to work as Genetic Counsellors in South Africa**

There are two processes:

#### **1. Reciprocity agreement:**

Candidates (Recognised Genetic Counsellors) from the UK and Australia will be assessed according to the reciprocity agreement between SA and these two countries (UK, Australia). (See transnational alliance for genetic counseling - <http://tagc.med.sc.edu>)

Candidates from these countries will be required to work in South Africa for a period of six months under the supervision of a registered genetic counsellor. During this period they have to have counselling supervision with an appropriately trained supervisor, including both individual and group supervision in accordance with the UK guidelines of at least one hour one-to-one supervision or 2 hours supervision in a group involving 4 members or less (AGNC Supervision Working Group 2007) per month. The candidate should submit a condensed portfolio following this period consisting of the following:

- Evidence of 6 month work experience
- Evidence of counselling supervision
- Written piece comparing genetic counselling practice between the home country and South Africa
- Three references

#### **2. Foreign applicants from countries which are not part of the reciprocity agreement:**

Candidates need to submit official documentary evidence of meeting the academic requirements and the internship training required for registration. These applications will be assessed on a case by case basis.

Foreign applicants may be required to complete a 24 month internship or part thereof at an accredited facility in South Africa and may be required to submit a full portfolio of evidence.

### **Applications from South African Genetic Counsellors to the UK or Australia**

The same criteria as stipulated in point 1 will apply. However as the UK has a 24 month post degree internship, newly qualified genetic counsellors will be required to complete an additional 12 month internship. Genetic Counsellors with 2 or more years of experience will not be required to do any additional internship training.

# INTERN TRAINING GUIDELINES

## Introduction

In order to register with the Health Professions Council of South Africa (HPCSA) as a Genetic Counsellor in the category “Independent Practice”, a two year internship must be completed in an HPCSA accredited training facility under the supervision of an appropriate HPCSA registered group of genetic counsellors and medical geneticists. The purpose of the internship is to provide exposure and experience to a wide variety of genetic counselling cases so that the intern can attain the necessary skills and competencies to practice independently.

Genetic Counsellors will be required to enter the internship when they register for a MSc in Genetic Counselling degree. The internship is 24 months. Year one of the internship overlaps with year two of the MSc degree while year 2 of the internship is post degree. There are no guidelines for Genetic Counsellors for a shortened internship following the attainment of an MSc or PhD Degree in a related discipline or for migrating into the field, and cases will be dealt with on a case by case basis through the Committee for Medical Science.

For interns who are not progressing adequately, their internship training can be extended for a further 6 months. According to the regulations an intern can do an internship for a maximum of 4 years with a leave of absence of one year. When the internship is extended, the reasons should be identified and extra measures put in place to address these and this should be included in the portfolio.

## Entry requirements

To register with the HPCSA as an intern in Genetic Counselling, the individual must be registered for a MSc in Genetic Counselling at one of the accredited University training facilities.

## Competencies

The competencies that need to be attained by the Intern Genetic Counsellor are stipulated above on pages 5-6 of this document.

The competencies will be achieved through:

- participation in course-work (lectures, tutorials, problem-solving exercises)
- participation in seminars, conferences, workshops, journal club meetings
- tests and examinations, if appropriate
- self-study

- practice using resources (databases, books, internet)
- participation in patient case discussions
- presentations
- observations in clinics
- interaction with patients and health professionals
- counselling of patients under supervision and independently
- clinical and counselling supervision

## **Assessment process**

The intern will compile a portfolio of activities which will demonstrate that the elements of training have been completed and the competencies achieved. The portfolio will be submitted to the Committee for Medical Science of the Medical and Dental Board of the HPCSA, for a Board approved assessment.

Approximately one month before submitting the portfolio, an exit assessment should be conducted by the training facility. An assessment by an independent assessor needs to be conducted at some point during the intern training period. This could be an assessor who has not been directly involved with the training process or an external person. The candidate should complete an “Admission to Assessment” form (HPCSA doc) and send it to the Committee for Medical Science. The portfolio will be assessed by two assessors and an experienced moderator who will indicate whether they recommend the candidate to be registered in the category “Independent Practice”. Interns will be required to pay a once off fee to cover some of the costs for the assessments. This excludes the yearly HPCSA registration fees.

## **Portfolio guidelines**

The portfolio will document the assessment process over the internship period. The portfolio will include 8 sections as outlined below. Each portfolio must have a table of contents to enable the assessor to easily find relevant information. The MSc Genetic Counselling degree will provide evidence of theoretical knowledge and a copy of the degree certificate needs to be included in the submission.

### **Section 1: Intern Programme**

A copy of the training program received from the training facility on entering the programme, must be included.

### **Section 2: Logbook**

A summary of the patient logbook needs to be submitted. As a broad guideline, it should contain: the number of patients seen, the diagnosis and type of counselling session (first time, follow-up session, under supervision, independent etc). The summary should indicate cases seen during all three years i.e. years 1 and 2 (during the degree and year 3 (post degree)).

A minimum of 200 cases in a variety of settings should be seen. Every effort should be made to ensure a reasonable distribution of medical conditions in prenatal, paediatric, and adult genetics. In each of these categories a minimum of 20 cases (10%) should be seen.

### **Section 3: Discipline specific knowledge**

Evidence should be provided regarding specific genetic, scientific, medical and counselling knowledge. This could include lectures, seminars, courses, conferences, workshops, journal club and patient case discussions attended.

### **Section 4: Assignments**

Specific assignments done should be categorized and listed with the marks/symbols achieved. If external moderators were used this should be indicated. The following could be included, if appropriate: problem based learning (PBL), presentations, tests and examinations.

### **Section 5: Ongoing Assessments**

Self-assessments, together with the trainer's and supervisor's appraisals, should be performed at specific intervals and these reports should be included. Remarks regarding observations, suggestions, amendments, progress according to the time-schedule should form part of the performance report. Evidence of involvement of an external examiner should be included. In line with the reciprocity agreement the following also needs to be provided:

- . Three written case reports (2000-3000 words) highlighting an ethical, medical and psychosocial issue respectively.
- . A reflective piece (2000-3000 words) based on a recording (voice or video) of a genetic counselling session. This should include a reflection written by the counselling supervisor. It is not necessary for the recording to be submitted with the portfolio but it should be available on request from the examiners.

### **Section 6: Research experience**

An abstract of the research report, examiners' reports and approved ethics certificate for the project should be submitted. Any publications such as peer-reviewed articles, abstract submissions for an oral or poster presentations at national/international conferences and awards obtained for the research should be noted.

### **Section 7: Final assessment by training facility**

The final assessment by the training facility which includes a list of competencies achieved should be submitted.

### **Section 8: Evaluation of the intern experience**

An evaluation of the training experience completed by the applicant should be included (HPCSA form).

## REFERENCES

1. American Board of Genetic Counseling (ABGC). Genetic Counsellors' Scope of Practice (approved by the NSGC in June 2007). Website: [www.abgc.net](http://www.abgc.net).
2. Genetic Counsellors in the UK: setting the scene. Meeting with the Health Professions Council, London, UK. 3 July 2007.
3. Kromberg JGR, Wessels T-M, Krause A. Roles of Genetic Counsellors in South Africa. *Journal of Genetic Counselling* (Awaiting decision)
4. National Society of Genetic Counsellors (NSGC). Definition of Genetic Counselling. *Journal of Genetic Counseling* 2006; 15: 77-82.
5. Supervision Working Group on Genetic Counselling Supervision 2007. Working Group: Alison Clarke, Anna Middleton, Lorraine Cowley, Penny Guilbert, Rhona Macleod, Angus Clarke, and Van Tran. Report from the UK and Eire Association of Genetic Nurses and Counsellors (AGNC). *Journal of Genetic Counseling* 2007;16(2):172-142

### Documents obtainable from the HPCSA website

<http://www.hpcsa.co.za>

1. Regulations defining the **scope of the profession** of medical science (R. 579) Government Gazette No. 32244, 22 May 2009.
2. Regulations relating to the **registration of interns** in medical science (R. 578) Government Gazette No. 32244, 22 May 2009.
3. Regulations relating to the qualification for **registration of medical scientists** (R. 581) Government Gazette No. 32244, 22 May 2009.
4. **Rules of conduct** pertaining specifically to the Medical and Dental profession Government Gazette No. 29079, 4 August 2006
5. **Extract from the Minutes** of the Nineteenth Meeting of the Committee for Medical Science with Genetic Counselors, Medical and Dental Profession Board, HPCSA, 12 May 2010

### Forms obtainable from the HPCSA website

<http://www.hpcsa.co.za>

1. Application for Intern Training : Genetic Counsellor (Form **26 GCIN**)
2. Intern Training Certificate : Genetic Counsellor (Form **36 GC**)
3. Registration form : Genetic Counsellor (Form **24 GC**)
4. Admission to assessment form (Available soon)
5. Evaluation of the intern experience (Available soon)