

Genetic Counselling No: 014D

1. Introduction

Genetic counselling is a communication process which deals with the human problems associated with the occurrence, or risk of occurrence, of a genetic disorder in a family. Genetic counselling is presumptive identification of an unrecognised genotype in individuals or populations.

Genetic screening is usually divided into three parts: (1) to detect the presence of disease, (2) to provide reproductive information, and (3) to gain information concerning the incidence of a disorder in the population. For the purposes of this study (1) and (3) will be required.

The success of counselling is measured by the way in which the family uses the information presented to them.

2. Responsibilities

Research nurses trained in the method are responsible for counselling families. It is the responsibility of the Nurse Co-ordinator to ensure that all research nurses are familiar with the requirements of Genetic counselling.

3. Equipment

None

4. Method

The study aims to look at the inherited cause of High Blood Pressure by identifying 5 responsible genes. No genetic information will be provided to subjects or their GP's. All subject data will possess a unique ID code which will not be traced back to the subjects involved. This particular study will not need to address the issue of Antenatal screening.

The object of genetic counselling for this study, is to provide subjects with enough information so that they understand our aims and the importance of their family medical history. This will hopefully provide the project with sufficient information, such that the genes responsible for hypertension in a white European population can be identified.

- When counselling subjects it is best to find an opportunity where time is not critical to those involved. Counselling can be provided anywhere, over the telephone, at a GP surgery or at the subject's home.
- The object of successful genetic counselling is to clearly explain the nature and purposes of the study procedures, in a manner they can understand.
- Reporting of Genetic data is not mandatory and for the purposes of this study all subject data will be coded. Identifying genetic details back to individual subjects will not be possible. All data results will remain confidential, under the Data Protection Act.
- To comply with the ethical constraints of the study, no subject will ever know their genetic results. This ensures that the subject will not come across any insurance

complications as a result of donating blood for a genetics study.

- All subjects must sign a consent form before donating their blood for the study. No subject should donate blood unless they have been fully informed of the study.
- The purpose of genetic counselling in this study is to ensure that all subjects are fully aware of what is required of them. They should be able to feel comfortable in asking any questions they require. The answers should be provided in a manner and style that they can understand.
- All subjects entering the study do so voluntarily and should not be put off by the nurse suggesting that they are going to counsel them. Genetic counselling for this study is a method of monitoring hypertensive subjects in the UK, to detect the possible genes predisposing to this condition.
- Often when screening subjects for one study, unexpected results for something else may arise (e.g. high cholesterol). All results (with the exception of genetic details) will be provided to every subject's GP. It is then the responsibility of the GP to discuss any significant results with their patients.
- Each subject will have different counselling demands. Counselling requirements are based on the information provided by the subject to the nurse, regarding their family medical history. A careful, detailed family history is necessary to the counselling process.
- Each nurse taking family histories must allow a liberal amount of time both for data collection and counselling needs. The family history should be recorded in the form of a family tree (pedigree chart). See SOP 015 for more detail.
- The success of counselling is measured by the way in which the family uses the information presented to them.
- The objective for genetic counselling for this study is purely for health rather than inheritance.

5. Additional Information

None.

6. Reference Documents

Nuffield Council on Bioethics. 1996. Genetic Screening. Ethical Issues. London.