

# Safeguarding the information in a genetic family history

A pedigree includes information about the biological relationships within a family, the medical diagnoses and genetic status of family members. This information is usually obtained from one member who gives it in good faith, using details obtained directly from other family members. Information about medical diagnoses in the family may well be known to many people, including friends and acquaintances. However, genetic family information should be held in confidence, but as it may be used to advise other family members it is good practice to gain consent from the person who gave the pedigree for information sharing and make a note of this.

## The status of information from family pedigrees and its disclosure

Most individuals expressly state that they wish pedigree information and genetic test results to be available to other family members and professionals to assist in diagnosis and medical care.

Recording information about other people in a family (and passing it to health professionals) is permissible under the Data Protection Act (under Schedule 3) without the explicit consent of all those shown on the pedigree if the processing is necessary for medical purposes (including the purposes of preventative medicine, medical diagnosis, medical research, the provision of care and treatment and the management of healthcare services). This was the advice that The Joint Committee on Medical Genetics received from the Information Commissioner. The health professional should ask for and record consent that the pedigree may be shared with other members of the family if appropriate, and with other health professionals if necessary for the care of family members. If asked to release information, it is good practice to review the pedigree to try to ensure that only information relevant to the clinical purpose is released; for instance, it may not be necessary to give names on parts of the pedigree.

## Publishing genetic family histories as part of clinical and research studies

Of course, consent from the person giving the pedigree needs to have been obtained. There are some other considerations to be taken into account, because the pedigree can give a great deal of information about biological relationships and health status. If it is imperative that a pedigree needs to be published, it is recommended that the minimum amount of information which needs to be disclosed is given on the pedigree figure. For instance, unless needing to demonstrate the precise pattern of males and females (affected and unaffected) and ages of onset in the family, is it necessary to signify the sexes and ages of family members? For relatively rare conditions, it may be possible for families to identify their family and also deduce not only their status but also that of other family members.

## Reference

Consent and confidentiality in genetic practice: guidance on genetic testing and sharing genetic information (2005). Report of the Joint Committee on Medical Genetics. London: RCP, RCPATH, BSHG.

### Confidentiality and consent are paramount

- Store the genetic family history information safely to preserve confidentiality.
- As it may be helpful in advising other family members, gain consent from the person giving the genetic family history, for information to be shared with family members and health professionals.

