

## BOOK REVIEW

# Consent and confidentiality

## Consent and Confidentiality in Genetic Practice

Joint Committee on Medical Genetics  
 Royal College of Physicians of London, £15  
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It was a great pleasure to review this book owing to the practical impact on the increasingly relevant and urgent topic of genetic education in which I am deeply involved. Genomics is having an increasing impact on the diagnosis, prevention and treatment of common disease. Clinical geneticists are faced daily with an increasing number of requests by patients for genetic testing and genetic counselling. More professionals will be involved in testing, either directly or by studying the impact of testing on health-care provision. It is therefore essential that health professionals are well prepared to deliver such patient care that includes complex issues relating to consent and confidentiality of genetic information.

While specialist genetic services will continue to provide genetic diagnosis and counselling for a number of rare inherited conditions, practitioners in both secondary and primary care will need to be equipped to deal with initial patient enquiries, to have an awareness of the potential implications of family history, to offer information related to their specific area of practice and to refer individuals or families appropriately to

other health-care providers, possibly including specialist genetic services. This is of concern to the ESHG Education Committee, and the focus of some of the work of the current EuroGentest project is to address the need for standardisation of testing across Europe.

Although this book, *Consent and Confidentiality in Genetic Practice*, was written initially in the UK context, it is an essential tool that contributes to the European need for genetic education. The 40-page report prepared by the Joint Committee on Medical Genetics, subtitled 'Guidance on genetic testing and sharing genetic information,' provides coherent guidance on obtaining consent before genetic tests, on regulations for giving and sharing genetic information with family members and between professionals, and on genetic investigations on stored human tissue. Contributions were made by members of the Royal College of Physicians of London, the Royal College of Pathologists and the British Society for Human Genetics. Although it is intended that the discussions and recommendations will be of value to all specialities, it was written in

response to requests from genetics professionals in the United Kingdom for clarification on issues of consent and confidentiality in general practice.

This document clarifies the new regulations laid down by the Human Tissue Act 2004 and the Data Protection Act 1998, including the requirements for consent in DNA analysis in the United Kingdom. The report presents complex legal issues in clear and concise terms and identifies key practice points, listing documents that may be helpful when seeking consent.

The five principal sections of the report are as follows: (1) consent in medical genetic practice: general aspects; (2) giving and sharing genetic information; (3) genetic investigations on stored samples or archival pathological material; (4) The Human Tissue Act 2004, consent and DNA analysis; and (5) The Data Protection Act 1998 and the processing of medical genetic information.

It includes information on the use of counselling as part of the consent procedure, recording consent and who can give consent (with sections on children and adults with mental disability). Flowcharts for guided decision-making and simple consent forms can be photocopied for use in hospitals and clinics. Health-care staff working in genetic clinics or in other specialist areas where genetic testing is required can be supported by this document in their daily practice.

The report is due for review in June 2008 ■

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