

Educating Human Research Ethics Committees on Genetics. Is it ethical?

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With the increasing emphasis on genetic research, how much information do HREC members require to adequately review complex questions of genetic privacy, discrimination, familial information and large-scale biobanking activities? We investigated the appeal and effectiveness of undertaking education for HREC members.

Two education seminars and one interactive workshop were held for researchers, HREC members, genetic support group members, HREC administrators and Department of Health policy officers. One hundred and fifty-six (156) people from the target groups attended these events. The first seminar "Using human tissue for genetic research" explored ownership, management, governance and consumer perspectives of tissue banks, the 26 respondents (35% response rate) stated the information provided at the seminar was useful.

The second seminar "Consumer attitudes to genetics and databases" considered the National Statement, lay understanding of consent, consumer attitudes to genetics and health data and the ethical perspectives that might guide tissue banking. Most (90%,n=23) respondents indicated the information provided in the seminar would be useful to their HREC activities.

The more complex topic of 'familial comity' was undertaken in a facilitated workshop format with four case studies used to explore the ethical principles that were applied in reviewing them. Analysis indicates the generally accepted ethical principles of autonomy, beneficence, non-maleficence and justice were not routinely applied.

HREC members undertake a complex task, reviewing numerous and varied applications to carry out research. These seminars and workshops supplemented the limited training otherwise provided for HREC members. Our findings suggest further guidance about undertaking ethical review of genetics-related research is warranted.