ETHICS WATCH

Continuing review of genetics research

The role of research ethics boards (REBs) is to review and monitor research projects that involve human beings. Continuing review is an important component of ethics evaluation, because the initial evaluation is only valid if the information on which it was based remains consistent throughout the project.

But many local REBs are increasingly uncomfortable with their monitoring role when it comes to genetics research projects, and particularly those that are aimed at understanding the function of genes.

Traditionally, continuing reviews by REBs have mainly focused on the physical protection of participants and on the proper consent process. In pharmaceutical research, participants are physically involved in the research project, and close contact with the researchers is maintained throughout. This is not always the case in genetics research. That said, other important concerns need to be addressed, such as adequate protection of personal information, proper management of genetic results and future uses of the biobank created for the project. Therefore, the attention of the REB needs to shift away from the examination of serious adverse events reports, for example, to the collection, use and storage of DNA samples and data management.

Recent years saw an increase in the creation of long-term mega-biobanks. As researchers strive to understand the complex interactions of genes with other genes and with environmental factors, they increasingly need access to large numbers of DNA samples that are linked to health, familial, social and environmental data. Such long-term research initiatives call for close ethics monitoring. Whereas modern biobanks tend to be centralized, ethics approval and review mechanisms are paradoxically decentralized. REBs strive to ensure the continued respect for participants and their rights at the site of recruitment, and to monitor the ethical unfolding of the genetics research activities wherever the DNA samples and the research might be. For local REBs then, it is more difficult to monitor the centralized activities of a remote biobank and to ensure efficient review of the project on a continuing basis. Also, a decentralized model poses greater difficulties in coordinating sustained efforts that are aimed at protecting research participants.

Given the challenges of monitoring modern genetics research projects, there is an increasing recognition of the need for a new ethics governance model. Interesting approaches and models have started to emerge. In Estonia, for example, an ethics committee was created by law to specifically review and monitor the gene bank that was created for an important national initiative: the Estonian Genome Project (although their decisions are not binding)[1]. The same law also creates a Data Protection Supervision Authority, which oversees data and tissue management for the project[2]. The United Kingdom has created Multicenter Research Ethics Committees[3], which can approve and monitor these types of research project. Some suggest that privacy commissioners (or any other person or institutions responsible for the enforcement of privacy legislation) might be increasingly involved in monitoring research data.

Innovative research strategies call for innovative approaches to ethics monitoring. It is timely for the research community and policy makers to revisit the governance of genetics research and to make sure that we can effectively meet the challenges that are raised by modern genetics research.

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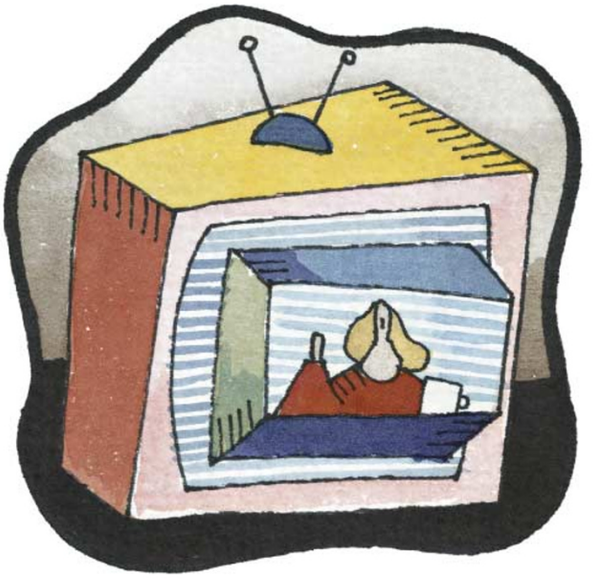

CANCER GENETICS

Developmental reruns

The idea that there might be a link between the genetic programmes of early development and oncogenesis is not new, although the nature of this relationship has remained largely unknown — that is, until now. Kho and Zhao *et al.* show that gene-expression profiles in solid tumours are strikingly similar to those seen during early mouse development.

The authors compared individual gene-expression profiles between human medulloblastomas (MB; tumours of the cerebellum) and mouse cerebella during the first 60 days after birth. They found that the genes that are expressed during early development tend to be upregulated in MBs, whereas those that are expressed late tend to be downregulated. But this correlation is not just MB-specific, for the authors demonstrate that a similar relationship is true also when expression profiles in squamous-cell carcinomas (tumours of the lung epithelium) are compared with those from the developing mouse lungs.

From looking at individual genes, Kho and Zhao *et al.* moved to a global analysis. This time, genomic expression profiles of human MBs were 'mapped' onto a genomic profile of a developing mouse cerebellum. Reassuringly, their first observations were confirmed; they found that, in terms of gene-expression profiles, human MBs most resembled mouse cerebella during the first 10 days of development, whereas normal human cerebella were more similar to those from 30–60-day-old mice. Interestingly, the expression profiles of metastatic MBs most closely resembled those of cerebella from 5-day-old mice.

The work of Kho and Zhao *et al.* extends our knowledge of tumour clinical behaviour and provides a new diagnostic (and perhaps even prognostic) tool. But the authors also pave the way to answering some intriguing tumour biology questions — for example, now that we know that whole developmental programmes are repeated during tumour progression, the theory that tumours originate from stem cells will, no doubt, be revisited.

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References and links

ORIGINAL RESEARCH PAPER Kho, A. T. & Zhao, Q. *et al.* Conserved mechanisms acrosss development and tumorigenesis revealed by a mouse development persepctive of human cancers. *Genes Dev.* **18**, 629–640 (2004)