

PATIENT NOTIFICATION AND DISSENT

Cancer risks in A-T carriers

Between 1998 and 2004, The University of Birmingham (Prof. A.M. Taylor) and University of Cambridge (Prof. D.F. Easton) carried out a study of cancer risks in 1160 relatives of 169 UK A-T patients. This was published in 2005 (J. Natl Cancer Inst. 97; 813-822) and the study showed that there was about a doubling of the risk of breast cancer in female *ATM* mutation carriers. This information was used to change the rules about breast cancer screening in *ATM* mutation carriers. In addition there was some evidence of an excess risk of some other cancers.

Since 2005, there have been registrations of further cancers and cancer deaths among this same group of 1160 relatives and so we would now like to examine these in order to see if the increased risk of breast cancer is still obvious and if there is a significant increased risk of other cancers. We believe that this will maximise the results possible from this study and make the most of the information now available, with no further action required from these A-T families.

As part of the requirements of the Data Protection Act, however, we have obtained permission from the government Confidentiality Advisory Group to allow us see if any of the names of these 1160 A-T relatives are also now on the list of registered cancer patients and indeed deaths in the UK. We do not release the names of individuals involved at all. And once we have gained access to this confidential data and made our calculations of cancer risk, confidentiality is imposed again.

You may be content to allow your data to be used for this purpose. However, if you feel you might be one of these 1160 relatives you have the right to object to your name being used to make a link with the cancer data. As a relative you may not have given personal consent, all those years ago, for this link to be made and you may want to object to this link being made now. If so please contact either of the two leads for this research and you can opt out of taking part in this extended study.

Leads for the study

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