

THE ACCEPTABILITY OF USING CONFIDENTIAL PATIENT INFORMATION WITHOUT CONSENT

Cancer risks in A-T carriers

In the 'Patient Notification and Dissent' document I hope that it is clear what we would like to do, that is to update the cancer risk in the 1160 relatives of A-T patients that we compiled back in 1998-2004.

As one of the 1160 relatives you may not have given personal consent, all those years ago, for the link to be made between your name and the names of people in the UK who have developed cancer. This is what we were able to do in that earlier period.

Do you feel that it is still acceptable to use confidential patient information without consent for the purposes of the type of research have I described above? The Confidentiality Advisory Group are keen to know if you feel that our research group has been sufficiently engaged with you over this issue. If you wish to respond either positively or negatively to this please write to me at A.M.R.Taylor@bham.ac.uk.

Of course if you want, you can opt out of taking part in this extended study as discussed above.