

Ethics watch

TAKING DNA FROM THE DEAD

Using cadaveric specimens in genome research presents many benefits: investigators can study multiple organs from one individual, including those impossible to collect from living donors (for example, brains), and health risks are minimized as the individual is deceased. Several genomic research initiatives plan to collect cadaveric tissues. For instance, the Genotype-Tissue Expression (GTEx) project, a US National Institutes of Health Roadmap initiative, is seeking insights into the mechanics of gene regulation by identifying variations in gene expression that are highly correlated with genetic variation¹. Another example is the Allen Institute for Brain Science's human brain atlases, which seek to create a comprehensive three-dimensional map of gene expression in the human brain². However, in many countries, including the United States, there are not adequate ethical guidelines in place for this type of research.

Scandals involving the removal and retention of organs from cadavers in the United Kingdom led to enactment of the Human Tissue Act, which makes it a crime to conduct genome research using tissues from cadavers without consent³. In the United States, cadaveric specimens can be obtained and used for most research with little regulatory oversight, no ethical review and without informed consent. Deceased individuals are not human subjects under US federal regulations⁴. Although the Revised Uniform Anatomical Gift Act recommends that states require individual or family permission to retain cadaveric tissues for use in research⁵, permission is not the same as informed consent. When an anatomical gift is made, only the purpose of the gift is specified (for example, transplantation, therapy, research or education); no discussion of the nature of the research or its risks, benefits and alternatives is required.

However, ethically, individuals retain certain interests after death, including an interest in having their bodies treated with respect and in having their ante-mortem wishes upheld⁶. Living individuals whose organs may be used for research post-mortem may also suffer present harm in anticipation that their corpse will be treated in ways that violate their values or beliefs. Also, family members (whether

genetically related or not) have an interest in the disposition of a loved one's remains. Finally, the use of cadaveric tissues in genome research raises additional concerns about privacy. Some have argued that deceased individuals can suffer non-experiential harm, such as loss of reputation that may result from a privacy breach after death⁶, and close genetic relatives have privacy interests that deserve protection⁷. Research has shown that DNA is a unique identifier^{8,9}, and in some forensic cases it has been used to identify the biological relatives of a suspect¹⁰.

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For these reasons, it is recommended that research on the newly dead is subjected to independent ethical review and that informed consent is obtained from the individual before death or from the legally authorized surrogate^{7,11}. The informed consent process should be integrated into existing organ procurement processes to allow priority to be given to transplanting viable organs and to avoid duplicate requests, and it should include an explanation of the potential privacy risks for the sample source, as well as her or his close genetic relatives. In addition, precautions should be taken to protect privacy by limiting access to DNA data through restricted databases¹². However, independent informed consent from genetic relatives should not be required because the risks are extremely small in relation to the burdens such a requirement would impose on the research. DNA will only reveal predictive information about biological relatives, and the risk of identifiability is both uncertain and dependent upon the nature of the data and the degree of relatedness to the sample source.



Further, in most cases it would be impracticable to identify and locate all potentially affected relatives, and the contact itself might constitute a breach of privacy.

Further research will be needed to ensure that new policies are responsive to the concerns and perspectives of potential donors and their families. In the absence of data regarding public perspectives, we recommend a preventative ethics approach that involves institutional review board appraisal and informed consent from the individual or a surrogate. This approach may prevent future scandals and bolster public trust. At the same time, it is not overly burdensome and so should not substantially impede research.

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