

You can't take your genes with you: Strategies to share genetic information after death

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Does the child of a person with a heritable form of cancer have the right to access their parent's genetic information after death? What if no consent was ever established? In the March 2 issue of *Trends in Molecular Medicine*, biomedical ethicists review current arguments about how to disclose genetic information of the deceased and offer suggestions that may help clinicians and officials develop their own policies.

A number of arguments exist both for and against such postmortem disclosure. Disclosure could promote a relative's health or well-being and could help them take more control over their lives. At the same time, it could also violate [family members'](#) right not to know and could cause psychological, financial, or other harm. Disclosure efforts might also face logistical challenges as healthcare professionals work to contact, inform, and counsel at-risk relatives.

"The first question that comes to mind is whether a clinician should communicate findings at all," says lead author Sarah Boers, MD, a PhD candidate at the University Medical Center Utrecht in The Netherlands. "This could mean a breach of confidentiality; however, we conclude that sometimes findings are so important that this overrides confidentiality."

Second, should the clinician only communicate findings if family members ask for it, or should they actively approach family members to

inform them? "For now, it is too far-reaching to actively approach family members, for example because of confidentiality and a family member's interest in not knowing," Boers says. "In addition, more public awareness about new sequencing techniques should be raised first, and proper guidelines should be developed."

Boers and her colleagues argue for passive postmortem disclosure policies, meaning that under certain circumstances access to [genetic information](#) should be provided to a deceased patient's family members at their request. They recommend that policies be crafted by clinicians and clinical institutions, as well as by professional, national, and ethics committees. The investigators also propose some urgent topics for further research, including patients' and family members' attitudes towards communication of genetic findings after death. Cultural differences across countries may make it inappropriate to adopt a single international policy.

More information: "Postmortem disclosure of genetic information to family members: active or passive?" Boers et al. *Trends in Molecular Medicine*, 2015.

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