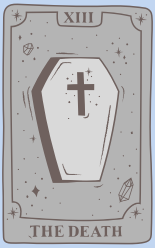
Posthumous Genetic Testing: Ethical Boundaries of DNA After death

Imagine unexpectedly dying, and a medical practitioner cutting open your body to sample parts of your DNA for testing. Sounds gruesome, I know. But this is one of the sole ways of delivering a body autopsy to identify the cause of death, especially in sudden or peculiar cases. However, imagine immense family drama arising...a long lost relative appears out of the blue, a mysterious hidden affair comes to light, or you somehow have alleged ties to a notorious crime. You may be thinking, This is the kind of stuff that only happens in movies, but it may be more common than you think. And being dead, having somebody pluck out pieces of your decaying hair or teeth to solve these unusual situations, may adhere to your moral code, but the dead can’t speak. This is why it is essential to address a not-too-commonly thought-out but imperative question: what consent and privacy concerns arise when the subject is gone?”

The World Medical Association Declaration of Geneva, for example, says, “I will respect the secrets which are confided in me, even after the patient has died”. The British Medical Association and the General Medical Council (GMC) also consider that the “duty of confidentiality continues after a patient has died”. Does this duty mean that a deceased patient’s medical information should never be released, and does the context of such a release matter?

So how is it possible for a deceased person to give consent to use their DNA? It’s not, and is followed by a torrent of boundless complications. First off, using someone else's DNA without their agreement could be problematic, particularly if the information needed relates to a family secret or a health danger. Family relationships may also be strained if genetic information from a deceased individual is shared, especially if it discloses events like unexpected fatherhood, illness predispositions, or other influencing circumstances. Secondly, numerous privacy concerns arise due to the relationality between relatives. Information regarding an individual may reveal crucial information regarding another, leading to a breach in their privacy. The privacy of living relatives whose genetic information is indirectly revealed through the data of the deceased person is called into question by this. Although there are some regulations in place to protect genetic data, the risks of it being misused or invaded must still be considered, as it could expose sensitive genetic information about other people. However, sharing genetic information from the deceased can help living relatives in life-threatening situations, such as identifying diseases, and could even have a redemptive value. Researchers and healthcare providers may face a "duty to inform" relatives about potentially actionable genetic findings discovered in the deceased's DNA, but this must be balanced against the deceased's privacy wishes and the potential impact on living relatives.



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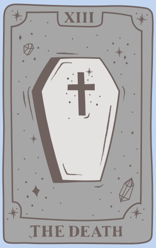
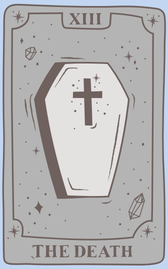


Ethical and privacy regards make us wonder, in case a similar situation would strike, what backup measures must be kept in place to protect the private data of relatives? This is where NoKs, or a term known as ‘Next of Kin’ comes into play. NoK largely refers to the closest living relative of the deceased, and is often asked in terms of healthcare in medical centres - it could be a relative or also an incredibly close family friend. The purpose of an NoK is to help inform and make decisions if a person is deceased, or any circumstance prevents them from doing so, essentially a representative of the patients opinion and interests, but have no legal right to give consent or make decisions for the patient, not essentially helpful in the case of a deceased person. However, most law systems, including UK law do not identify NoK as an official term in genetic matters.

At times, samples taken before the death of a person are presumed to have ‘consent’ for the removal and storage of DNA. If any additional testing takes place after death, extra consent is not required if it is to improve or obtain new results from a previously conducted test. However, improving these results are often due to the request of a relative to obtain genetic information, but is debatable when questioning further consent is required.

Genetic testing after death is at the intersection of ethics, privacy and medical advancement. Although providing consent is out of the question for the deceased, their DNA often contains vital information that could be crucial to the lives and wellbeing of living relatives. This challenges the promise of confidentiality and revealing significant health findings to others. For such circumstances, current measures lack the clarity required to do so, however, abiding by the ethical concerns raised, the matter solely depends on the interests of the deceased and the involved living. The advancement of genetic research calls for a more thoughtful, comprehensive approach that respects the dignity of the dead while also acknowledging the legitimate rights of the living.



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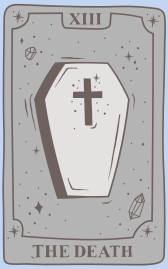

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