

GENETICS

INFORMED CONSENT FOR GENETIC DATA BEFORE 1997

15.03.2024

I was involved in a controversy [back in 2005](#) where I opposed the view that

it should be possible to perform research without informed consent if the samples and data are anonymized or pseudonymized

Glad to see a new correspondence letter in [Nature on March 12](#)

since the 1997 UNESCO Universal Declaration on the Human Genome and Human Rights, there has been a clear duty to obtain informed consent for human genetic research. But we did not conclude that human genetic data collected before 1997 were exempt from the need for informed consent. Rather, without recognized international standards, imposing a duty to retroactively obtain consent documentation from data providers is challenging.

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