Subject: Research Handling of De-Identified Patient Information

Presented by: Peter A. Schwartz, MD, Chair

Policy D-315.969 adopted in November 2021 directs the Council on Ethical and Judicial Affairs to “consider re-examining existing guidance relevant to the confidentiality of patient information, striving to preserve the benefits of widespread use of de-identified patient data for purposes of promoting quality improvement, research, and public health while mitigating the risks of re-identification of such data.”

Independently, at its August 2021 meeting the Council concluded that in light of the complex issues arising with the rapid development of data science and increasing research use of large health-related data sets, along with recent changes in the Common Rule governing research with human participants, it would reconsider guidance in Opinion 7.3.7, “Safeguards in the Use of DNA Databanks” and would in addition review other existing guidance on confidentiality last updated in 2016 as part of the overall project to modernize the AMA Code of Medical Ethics.

This review is ongoing. The Council anticipates submitting its preliminary report to the House of Delegates at the June 2023 Annual Meeting.