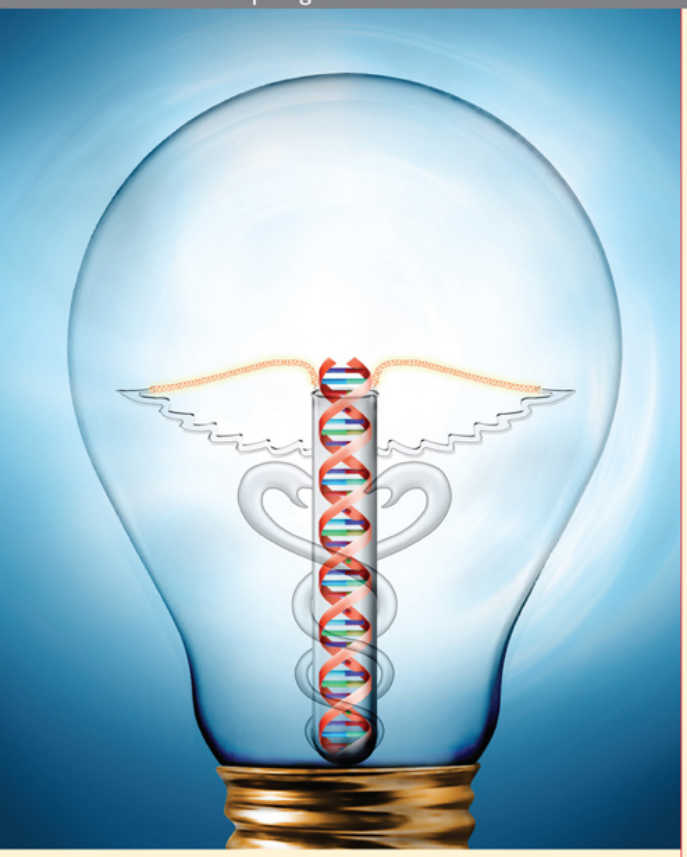
THE JOURNAL OF
LAW, MEDICINE & ETHICS

Volume 48:1 • Spring 2020

A Journal of the American Society of Law, Medicine & Ethics • www.aslme.org



INDEPENDENT ARTICLES

SYMPOSIUM

LawSeq: Building a Sound Legal Foundation for Translating Genomics into Clinical Application

GUEST EDITED BY Susan M. Wolf, Ellen Wright Clayton, and Frances Lawrenz

Plus more inside...

jlme.sagepub.com
ISSN: 1073-1105

https://doi.org/10.1017/S1073110500023718 Published online by Cambridge University Press

The Journal of Law, Medicine & Ethics (JLME): Material published in *The Journal of Law, Medicine & Ethics* (JLME) contributes to the educational mission of the American Society of Law, Medicine & Ethics, covering public health, health disparities, patient safety and quality of care, and biomedical science and research, and more.

Editorial Office
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Letters to the Editors: Comments on articles in the Journal should be addressed to the Editor at the editorial office or emailed to thutchinson@aslme.org.

Submission Guidelines: For submission guidelines, please contact the editorial office at thutchinson@aslme.org. Submission guidelines are also available online at http://journals.sagepub.com/home/lme.

The Journal of Law, Medicine & Ethics (ISSN 1073-1105) (J812) is published quarterly—in March, June, September and December—by SAGE Publishing, 2455 Teller Road, Thousand Oaks, CA 91320 in association with the American Society of Law, Medicine & Ethics. Send address changes to the Journal of Law, Medicine & Ethics, c/o SAGE Publishing, 2455 Teller Road, Thousand Oaks, CA 91320.

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Symposium Articles

https://doi.org/10.1017/S1073110500023718 Published online by Cambridge University Press

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Symposium articles *are solicited by the guest editor for the purposes of creating a comprehensive and definitive collection of articles on a topic relevant to the study of law, medicine and ethics. Each article is peer reviewed.*

Independent articles *are essays unrelated to the symposium topic, and can cover a wide variety of subjects within the larger medical and legal ethics fields. These articles are peer reviewed.*

Columns *are written or edited by leaders in their fields and appear in each issue of JLME.*

Next Issue:

Opioid Controversies: The Crisis — Causes and Solutions

A Symposium Guest Edited by Robert M. Sade

Dynamic Consent (DC) is both a model and a specific web-based tool that enables clear, granular communication and recording of participant consent choices over time. The DC model enables individuals to know and to decide how personal research information is being used and provides a way in which to exercise legal rights provided in privacy and data protection law. The DC tool is flexible and responsive, enabling legal and ethical requirements in research data sharing to be met and for online health information to be maintained. DC has been used in rare diseases and genomics, to enable people to control and express their preferences regarding their own data. However, DC has never been explored in relationship to historical collections of bioscientific and genetic heritage or to contexts involving Aboriginal and Torres Strait Islander people (First Peoples of Australia).

In response to the growing interest by First Peoples throughout Australia in genetic and genomic research, and the increasing number of invitations from researchers to participate in community health and wellbeing projects, this article examines the legal and ethical attributes and challenges of DC in these contexts. It also explores opportunities for including First Peoples' cultural perspectives, governance, and leadership as a method for defining (or redefining) DC on cultural terms that engage best practice research and data analysis as well as respect for meaningful and longitudinal individual and family participation.

Columns

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