

Bioethics and Humanities Newsletter

PROGRAM IN BIOETHICS AND HUMANITIES, CARVER COLLEGE OF MEDICINE

May 2018

UPCOMING EVENTS

For a list of more upcoming events related to bioethics and humanities, [click here](#).

QUOTATION OF THE MONTH

There is a significant mismatch between parents' expectations and those of pediatric surgeons about the role of the surgeon on the day of operation, with parents consistently expecting more direct involvement by the attending surgeon.

Choe et al. ([J Am Coll Surg](#), 2018)

UIHC ETHICS CONSULT SERVICE

This service is a resource for patients, family members, or health professionals at UIHC who would like help addressing an ethical question or problem related to a patient's care. Consults can be ordered by UIHC clinicians through EPIC. Consults can also be requested by calling (319) 356-1616 and asking for the ethics consultant on call. For more information, [click here](#).



Welcome to the monthly Bioethics and Humanities Newsletter provided by the Program in Bioethics and Humanities at the University of Iowa Carver College of Medicine.

Program in Bioethics and Humanities: *Our Mission*

We are committed to helping healthcare professionals explore and understand the increasingly complex ethical questions that have been brought on by advances in medical technology and the health care system. We achieve this through education, research, and service within the Carver College of Medicine, University of Iowa Health Care, University of Iowa, and the wider Iowa community.

[More Details About The Program](#)

PROGRAM HIGHLIGHT ETHICS IN HEALTHCARE 2018



[ETHICS IN HEALTHCARE 2018](#)

A One Day Conference for Collaborative Dialogue and Inter-Professional Exchange

Date: May 18, 2018

Time: 7:45 AM – 4:30 PM

[REGISTER NOW!](#)

CLINICAL RESEARCH ETHICS SERVICE

We provide free consultation on ethical issues related to research design, tissue banking, genetic research results, informed consent, and working with vulnerable patient populations. In particular, we assist clinical investigators in identifying and addressing the ethical challenges that frequently arise when designing or conducting research with human subjects. These include ethical challenges in sampling design; randomized and placebo-controlled studies; participant recruitment and informed consent; return of individual-level research results; community engagement processes; and more. For more information, [click here](#).

READING ETHICS AT UIHC

If you are interested to see what the UIHC Ethics Subcommittee was reading in March, [click here](#).

HISTORY OF MEDICINE SOCIETY

The University of Iowa History of Medicine Society invites you to visit the [John Martin Rare Book Room website](#). On this website you will find resources, [digital exhibits](#), and news/highlights, such as [Notes from the Rare Book Room](#).

PROGRAM HIGHLIGHT ANNIE JANVIER, MD, PhD

INTENSIVE CARE FOR FRAGILE NEONATES: WHAT IS THE VALUE OF LIFE?



[Annie Janvier, MD, PhD](#)

Associate Professor, Dept. of Pediatrics, Univ. of Montreal
Neonatologist & Clinical Researcher, NICU, CHU Sainte-Justine
Member, Clinical Ethics Unit, CHU Sainte-Justine
Co-Director, Microprogram & Master's in Pediatric Clinic Ethics,
Univ. of Montreal

Date: May 18, 2018

Time: 10:15-11:45 AM

Location: 1110 MERF (Medical Education Research Facility)

Intended Audience: Open to the UIHC Community

PUBLICATION HIGHLIGHT

Analysis of state laws on informed consent for clinical genetic testing in the era of genomic sequencing

Kayte Spector-Bagdady, **Anya E. R. Prince**, Joon-Ho Yu, Paul S. Appelbaum

Abstract

This article assesses the adequacy of informed consent to clinical genetic testing laws based on an examination of 15 states with institutions that had been involved in a National Institutes of Health-supported Clinical Sequencing Exploratory Research Consortium project. We identified relevant statutory provisions through a legal search engine and included statutes that describe the informed consent requirements for clinical genetic testing and/or the protections for genetic material, information, or data. We found that statutory definitions were often limited in problematic ways, such as focusing only on variants known to be associated with disease or negative health effects or associated with asymptomatic disease. Some statutes required complex levels of detail if applied to genomic technologies and set confusing disclosure standards for current use and future access. Others had exceptions from informed consent requirements for future research use, limited requirements for the destruction of specimens as opposed to derived data, or linked key definitional components to the evolving concept of "identifiability." Further reform and research are needed to ensure that state law protections advance as rapidly as the science they aspire to enable. To read the full article, [click here](#).

HISTORY OF MEDICINE SOCIETY

EXHIBIT

Humans in Medical Experiments: Issues of Social Justice

*March 2018 to Fall 2019
Hardin Library for the Health Sciences, 3rd Floor*

Exhibit highlights eleven instances of human experimentation from 1796 to 2013. Displays include early experiments on digestion and X-rays, WWII experiments by the Nazis and Japanese, experiments for the Manhattan Project, Atomic Energy Commission, and Holmesburg Prison. Panels and materials provided by the University of Iowa Human Subjects Office describe the past, present and future of Protection of Human Research Subjects.



William Beaumont
1822-1833



William Morton and the X-ray
1896-1905



Holmesburg Prison
1951-1974

RESOURCE HIGHLIGHT

RESEARCH ETHICS CASE STUDIES

The [Center for Clinical and Research Ethics \(CCRE\)](#) is a unit of the Division of General and Medical Sciences in the Washington University School of Medicine in St. Louis. The CCRE's mission is to support evidence-based ethics in research and clinical practice.

The CCRE supports a variety of educational programming including an [online research ethics case compendium](#). The cases cover a broad range of research ethics topics, including the Belmont Report, informed consent, privacy and confidentiality, genetic research, vulnerable populations, and research integrity. Each case contains a brief description, keywords, and several questions.



BIOETHICS IN THE LITERATURE

- ⇒ Choe JK, Ibarra C, Feinn RS, et al. Concurrent surgery and the role of the pediatric attending surgeon: Comparing parents' and surgeons' expectations. [J Am Coll Surg](#). 2018 Apr 12. [Epub ahead of print]
- ⇒ Kater-Kuipers A, de Beaufort ID, Galjaard R-JH, et al. Ethics of routine: A critical analysis of the concept of 'routinisation' in prenatal screening. [J Med Ethics](#). 2018 Apr 25. [Epub ahead of print]
- ⇒ Kirsch MJ, Kasten SJ. What about learners' roles in the operating room should be disclosed to patients? [AMA J Ethics](#). 2018; 20: 336-341.
- ⇒ Kraft SA, Cho MK, Gillespie K, et al. Beyond consent: Building trusting relationships with diverse populations in precision medicine research. [Am J Bioeth](#). 2018 Apr; 18: 3-20.
- ⇒ Lantos JD. Neonatal research ethics after SUPPORT. [Semin Fetal Neonatal Med](#). 2018 Feb; 23: 68-74.
- ⇒ Licurse AM, Mehrotra A. The effect of telehealth on spending: Thinking through the numbers. [Ann Int Med](#). 2018. [Epub ahead of print]
- ⇒ Morris DB. Optimal relief for pain at the end of life: A caregiver's tale. [Med Humanit](#). 2018 Apr 18. [Epub ahead of print]
- ⇒ Schaefer GO, Savulescu J. The right to know: A revised standard for reporting incidental findings. [Hastings Cent Rep](#). 2018 Mar; 48: 22-32.
- ⇒ Shah SK, Kimmelman J, Lyerly AD, et al. Bystander risk, social value, and ethics of human research. [Science](#). 2018 Apr 13; 360: 158-159.
- ⇒ Shapiro J. Confronting unprofessional behaviour in medicine. [BMJ](#). 2018 Mar 7; 360: k1025.
- ⇒ Shinall MC, Jr. The evolving moral landscape of palliative care. [Health Aff \(Millwood\)](#). 2018 Apr; 37: 670-673.
- ⇒ Vogel L. Should doctors talk politics with patients? [CMAJ](#). 2018 Apr 23; 190: E520-E521.
- ⇒ Wiersma M, Kerridge I, Lipworth W. Dangers of neglecting non-financial conflicts of interest in health and medicine. [J Med Ethics](#). 2017 Nov 24. [Epub ahead of print]
- ⇒ Wilson ME. Saving a death when we cannot save a life in the intensive care unit. [JAMA Int Med](#). 2018. [Epub ahead of print]

BIOETHICS NEWS AND EVENTS

- ⇒ [Iowa City Native Returns Home to Fight the Harms of the Opioid Crisis](#). Iowa City Press Citizen, April 26, 2018.
- ⇒ [The Vaccine Dilemma: How Experts Weight Benefits for Many Against Risks for a Few](#). STAT News, April 23, 2018.
- ⇒ [Court Rejects Alfie Evans Appeal](#). BioEdge, April 21, 2018.
- ⇒ [The Surgeon who Experimented on Slaves](#). The Atlantic, April 18, 2018.
- ⇒ [Making Health Research Relevant – and Less Feared – in the Mississippi Delta](#). STAT News, April 18, 2018.
- ⇒ [Do Value Frameworks Fully Capture the Value of Innovation?](#) Health Affairs Blog, April 16, 2018.
- ⇒ [FDA Launches Criminal Investigation into Unauthorized Herpes Vaccine Research](#). Kaiser Health News, April 12, 2018.
- ⇒ [Here's What's in the FDA Plan to Include Pregnant Women in Clinical Trials](#). STAT News, April 10, 2018.

Registration is now open for several upcoming pediatric ethics webinars hosted by the Children's Mercy Kansas City Bioethics Center. For more information and to register, [click here](#).