Ethical Frontiers in the Brave New World of Genomics & Learning Health Systems

As a health professional, you will soon — if not already — find yourself dealing with the impact of advances in genomics and the demands of Learning Health Systems, where knowledge is drawn from every patient encounter.

Join your colleagues to learn what you need to know from internationally acclaimed experts, including a representative from the Presidential Commission for the Study of Bioethical Issues.

Friday, November 8
7:30 am – 4:00 pm

LOCATIONS

ONSITE
University of Kansas School of Nursing Auditorium
3901 Rainbow Blvd. • Kansas City, Kansas

iTV REMOTE
(Provided through the sponsorship of the University of Kansas)
Duke University
Fort Hays State University
Kansas State University
KU School of Medicine at Salina
KU School of Medicine at Wichita
MU Center for Health Ethics
Pittsburg State University
University of Kansas at Lawrence

SPONSORS
Center for Health Ethics, University of Missouri School of Medicine
Central Plains Geriatric Education Center
Children’s Mercy Hospitals & Clinics
Frontiers: The Heartland Institute for Clinical and Translational Research
Kansas City Area Life Sciences Institute
Missouri Telehealth Network
Saint Luke’s Health System
Seigfreid Bingham, P.C.
University of Kansas Medical Center
University of Missouri-Kansas City
UMKC School of Medicine
Discrepancies in public policy allow our genetic data to be handled differently, depending on the circumstances in which samples are taken. There is one set of rules for data collected for research and a more relaxed set of rules for data collected in clinical settings.

At the same time, health systems have an obligation to pursue continuous quality improvement in order to quicken the pace of discovery, reduce harm to patients and improve the efficiency of care.

To achieve these goals, traditional health systems must transform into Learning Health Systems. This will require the definition of research to be broadened to include data collection activities that we now normally regard as “routine patient care.”

What is the state of the science in human genome sequencing, and what are its implications for privacy? How adequate is informed consent in the application of whole genome sequencing in research and clinical settings? What are the obligations of patients and providers to participate in research related to routine patient care?

Overprotective research ethics protocols can stall progress. Underprotection of human subjects exposes patients to significant risk without oversight. What ethical framework do we need to advance research while protecting human subjects in Learning Health Systems? At this Symposium, you’ll gain insights to these and related issues on the ethical frontiers of genomics, research, clinical practice, policy and advocacy.
Symposium: Day at a Glance

7:30  REGISTRATION AND CONTINENTAL BREAKFAST

ETHICAL AND CLINICAL FRONTIERS IN GENOMIC MEDICINE

8:00  State of the Science in Genomic Medicine
  Stephen Kingsmore, MB, ChB, BAO, DSc, FRCPath

8:45  Ethical Analysis of Privacy Concerns in the Era of Genomic Medicine
  Misha Angrist, PhD, MFA

9:15  Ethical Analysis of Privacy Concerns in the Era of Genomic Medicine (Continued)
  Alan Rubel, JD, PhD

9:45  BREAK

10:00 Panel Discussion
  Barbara Atkinson, MD, and John Lantos, MD, moderated by Richard Payne, MD

ETHICAL CHALLENGES IN THE NEW ERA OF LEARNING HEALTH SYSTEMS

10:30  What is a Learning Health System?
  Richard Payne, MD

11:00  Cardiovascular Outcomes and the Learning Health System
  Mikhail Kosiborod, MD, FACC, FAHA

11:30  Biobanking and Big Data
  Mark Hoffman, PhD
  Director, Center for Health Insights,
  University of Missouri-Kansas City

11:45 Panel Discussion
  Misha Angrist, PhD, MFA, Barbara Atkinson, MD, Mikhail Kosiborod, MD, FACC, FAHA, and Alan Rubel, JD, PhD, moderated by Richard Payne, MD

12:15 LUNCH (Provided)

7:30  REGISTRATION AND CONTINENTAL BREAKFAST

ETHICAL CHALLENGES IN THE BRAVE NEW WORLD

1:00  Implications for Translational Research and Learning Health Systems
  Lauren S. Aaronson, PhD, RN, FAAN, and Richard Barohn, MD

1:40  Response
  John Carney, MEd, and Sarah McGraw, PhD

2:00  What Is Low-Risk, Low-Burden Research, What Protections Are Needed, and What Are Caveats to Changing the Common Rule?
  Mikhail Kosiborod, MD, FACC, FAHA, and John Lantos, MD

2:30 Panel Discussion
  Barbara Atkinson, MD, and Alan Rubel, JD, PhD

3:00 Center for Practical Bioethics Response Panel
  Barbara Atkinson, MD, Richard Payne, MD, and James L. Spigarelli, PhD

3:45 Closing Remarks and Evaluation
  John G. Carney, MEd
Symposium Registration
Genomics & Learning Health Systems

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Send check made out to Center for Practical Bioethics and form to:
Center for Practical Bioethics
Harzfeld Building
1111 Main Street, Suite 500
Kansas City, MO 64105-2116
Attn: Nov. 8, 2013 Symposium

Questions? Call Cindy Leyland 816-979-1357
Email form: cleyland@practicalbioethics.org
Fax form: 816-221-2002

Location Options*
Please check one.

Onsite ($129)
☐ University of Kansas School of Nursing Auditorium

iTV Remote ($79)
☐ Duke University
☐ Fort Hays State University
☐ Kansas State University
☐ KU School of Medicine at Salina
☐ KU School of Medicine at Wichita
☐ MU Center for Health Ethics
☐ Pittsburg State University
☐ University of Kansas at Lawrence

* For details on locations, go to www.practicalbioethics.org.

Continuing Education

Physicians
Children’s Mercy Hospitals and Clinics is accredited by the Missouri State Medical Association to provide continuing medical education for physicians.

Children’s Mercy Hospitals and Clinics designates this live educational activity for a maximum of 6.75 AMA PRA Category 1 Credit(s)™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Nurses and Social Workers
This educational activity has been awarded 6.75 contact hours.

Children’s Mercy Hospitals and Clinics is an approved provider of continuing nursing education by the Missouri Nurses Association, an accredited approver by the American Nurses Credentialing Center’s Commission on Accreditation.

6.75 Social Work CEUs will be provided to licensed social workers.

Children’s Mercy Hospital’s Department of Social Work & Community Services has been approved as a Continuing Education Provider by the State of Kansas Behavioral Sciences Regulatory Board.

Attorneys
The Symposium has been approved for 8.0 CLE hours in Missouri and 8.0 CLE hours in Kansas. Affidavits will be available. Completed affidavits must be submitted to the Kansas Continuing Legal Education Commission within 30 days of the program.

Website Registration
www.practicalbioethics.org