If you were asked to participate in a national cohort study of 1 million people, where all of your genetic and associated clinical and environmental information would be deposited into a database and made available to researchers around the globe, would you do it?

On January 20, 2015, during his State of the Union Address, President Obama announced the Precision Medicine Initiative, which proposes to invest $215M in building the research and regulatory infrastructures necessary “to bring us closer to curing diseases like cancer and diabetes – and to give all of us access to the personalized information we need to keep ourselves and our families healthier.” Embedded within this Precision Medicine Initiative are several ethical, legal and policy issues that researchers in the Center for Medical Ethics and Health Policy have been addressing through our Ethical, Legal, and Social Implications (ELSI) research program. For example, President Obama calls for “a new way of doing research through engaged participants and open, responsible data sharing.” With support from Baylor College of Medicine, The Greenwall Foundation, the National Institutes of Health (NIH), and the Center for AIDS Research, we have spent many years engaging with research participants and exploring their willingness to openly share their health, medical, and genetic data. What we have found is that among individuals who are afflicted with illness and parents of children with chronic or severe medical conditions, the majority are very interested in doing whatever they can to contribute to research and so are willing to openly share their or their child’s data. However, there is a large minority who are either unwilling to share their data at all, or are only willing to share their data if there are stringent security measures in place to ensure that only bona fide researchers can access it. We are now beginning to explore what guiding principles are needed to maximize participation while respecting the varying perspectives of individual participants.

President Obama’s Personalized Medicine Initiative also highlighted the need for regulatory modernization to advance innovation while protecting the public health. With support from the NIH, we are exploring the clinical and psychosocial risks of clinical genomic sequencing through three large collaborative research projects: the Baylor Advances in Sequencing in Childhood Cancer Care (BASIC3) Project (PIs: Sharon Plon and Will Parsons, Baylor and Texas Children’s Hospital), the MedSeq Project (PI: Robert Green, Brigham and Women’s Hospital and Harvard Medical School), and the BabySeq Project (PIs: Robert Green and Alan Beggs, Brigham and Women’s Hospital, Harvard Medical School, and Boston Children’s Hospital). We are also engaging a diverse group of stakeholders using a modified Delphi process in the PoliSeq Project, (PI: Amy McGuire) to explore different policy options for addressing barriers to adoption and to help guide current efforts at regulatory reform.

Through these funded research projects, and the support we receive from all of you, the Center for Medical Ethics and Health Policy is well positioned to provide leadership and expertise in developing robust ethical and policy frameworks for new federal programs, such as this most recent Personalized Medicine Initiative. We thank you for your continued support and collaboration!

Amy McGuire, J.D., Ph.D.
Leon Jaworski Professor of Biomedical Ethics
Center Director

Become a Center Supporter
The Center’s mission is to conduct innovative multidisciplinary research on ethical issues arising in clinical practice and biomedical research. Your support will enable us to further this mission as we address ethical and policy challenges in healthcare and biomedical research, inform the education of trainees at all levels, and contribute to the development of health policy at the local, national, and international levels. In particular, your gift will support faculty research, Ethics Track student education, and community outreach activities. If you would like to talk to someone about making a gift or directing your gift to a specific project, please contact us or donate online now.
Ethics Track Accomplishments

Moving into 2015, we would like to recognize the achievements of several Ethics Track students, current and past. It is with the help of Center faculty, affiliates, and staff that the track is able to provide top-rated medical ethics education for Baylor medical students. Congratulations to all of our Ethics Track students and alumni on all of your accomplishments!

- First year ethics track student, Julika Kaplan, MS1, received an award from the Baylor Center for Globalization Scholarly Activity Grant in January 2015 for her project entitled, “An Investigation of the Relationship Between Autonomy, Childbirth Practices, and Obstetric Fistula among Malawian Women”.
- Arina, Chesnokova, MS2, has been named a guest editor of Virtual Mentor (AMA Journal of Ethics) during the 2015 – 2016 academic year.
- Rachel Conrad, MS4, was named a finalist for the Daniel Callahan Young Writer’s Prize by Bioethx Under 25.
- Benjamin Farnia, MS4, Dr. Mary Majumder, and Dr. Arnold Paulino from M.D. Anderson Cancer Center developed a paper that was presented at the 18th annual ASBH meeting and recently published in the Journal of the American College of Radiology titled “Ethical Analysis as a Tool for Addressing Treatment Controversies: Radiotherapy Timing in Children with Orbital Rhabdomyosarcoma as a Case Example”.
- Ethics Track alumnus, Dr. Mauricio (Tony) Escobar, Jr. and Dr. Laurence McCullough published two papers; “Responsibly Managing Ethical Challenges of Residency Training: A Guide for Surgery Residents, Educators, and Residency Program Leaders” and “Should General Surgery Residents Be Taught Laparoscopic Pyloromytomies? An Ethical Perspective”.

Are you an Ethics Track student or alumni who has published, presented, or received recognition related to your Ethics Track experience? We want to ensure we have an accurate catalogue of your Ethics Track related activities so please send any updates to Betsy Kusin.

Educational Resource Helping Residents Meet Milestones

Dr. Nathan Allen is leading the development of a new educational initiative for Baylor residents called the Ethics, Professionalism and Policy Program (EP3). EP3 combines e-modules and live engagement sessions in a curriculum that is tailored by specialty to meet the specific needs of residents and the ACGME Next Accreditation System. The program is currently live in the departments of emergency medicine, radiology and neurology and will soon expand to neurosurgery, urology and orthopedics.

Clinical Ethics

Register for the Intensive Bioethics Course

The Center and Houston Methodist Hospital are offering a week-long intensive bioethics training course, which will provide formal training in clinical ethics consultation May 11-15, 2015. The course covers cutting-edge bioethics topics and offers hands-on practice in developing policies, conducting and documenting consultations, conducting committee meetings, and mediating difficult conversations. Registration for the course is still open. Read more about the course in the TMC News article, "Lessons in Bioethics."
Dr. Jennifer Blumenthal-Barby and Dr. Amy McGuire collaborated with Dr. Peter Ubel from Duke University and Dr. Robert Green from Brigham and Women’s Hospital on a paper recently published in Genome Medicine, titled “How Behavioral Economics Can Help Avoid “The Last Mile Problem” in Whole Genome Sequencing.”

Professor Courtenay Bruce and colleagues published “A Qualitative Study Exploring Moral Distress in the Intensive Care Unit Team: The Importance of Unit Functionality and Intra-team Dynamics” in the Journal of Critical Care Medicine and “Like firemen going into a fire”: Moral Distress in the Intensive Care Unit” in ICU Management.

**Research Updates**

This PCORI funded research project (PI: Jennifer Blumenthal-Barby) addresses the need for patient-centered decision aids by conducting qualitative interviews with 15 LVAD patients, 15 LVAD candidates, 15 LVAD caregivers and 15 LVAD decliners to elucidate their values, goals and decision-making processes. From these interviews, as well as input from our multi-disciplinary team of surgeons, cardiologists, social workers, ethicists, decision scientists and patient partners, a patient-centered decision aid was created that presents outcomes, risks, experiences, and uncertainties about LVAD placement in a clear and unbiased manner to help patients with decision-making capacity make value-based decisions regarding their treatment. To learn more about the decision aid, please visit www.lvaddcisionaid.com. The project is now beginning the second phase of the study by testing the team-developed decision aid in a randomized controlled trial at five sites with a total of 144 subjects. This trial will be evaluating the decision aid’s impact on the decision-making process through various measures and scales such as decisional regret, knowledge, satisfaction with decision-making process, quality of life and others.

**Select Presentations**

Dr. McGuire presented at the 33rd David Barap Brin Visiting Professor in Medical Ethics at Johns Hopkins University School of Medicine on February 25th. Dr. McGuire’s presentation titled, “Genomics, Ethics and The Future of Precision Medicine” explores President Obama’s Precision Medicine Initiative and the ethical and policy challenges associated with these new initiatives.

**Select Publications**

Dr. Jennifer Blumenthal-Barby and Dr. Amy McGuire collaborated with Dr. Peter Ubel from Duke University and Dr. Robert Green from Brigham and Women’s Hospital on a paper recently published in Genome Medicine, titled “How Behavioral Economics Can Help Avoid “The Last Mile Problem” in Whole Genome Sequencing”.

**Center Events**

**Journal Club and Clinical Case Conference**

Journal Club meets monthly at 12-1pm in a brown-bag lunch, open-forum style. Anyone is welcome to attend and join in the conversation. The upcoming date for the monthly gathering is June 11, 2015. Clinical Ethics Case Conferences will take the place of Journal Club on a quarterly basis to create an environment for learning and analysis of interesting ethics cases.

The next Clinical Ethics Case Conference will be May 6, 2015.

**Grand Rounds**

The next Bioethics Grand Rounds will take place on May 20, 2015 and will address medical confidentiality, professionalism, and ethical challenges in the use of social media. Check out a complete list of topics and dates for our upcoming Bioethics Grand Rounds. Grand Rounds are held at Houston Methodist Hospital from 5-6pm in the Rio Grande conference room. Programs are intended for HMH healthcare professionals, but are open to anyone interested in attending.
Dr. Blumenthal-Barby collaborated with Center affiliates and published in Medical Decision Making “The Neglected Topic: Presentation of Cost Information in Patient Decision Aids” and “Biology, Metaphysics, and brain death criteria” in the Journal of Critical Care.

Dr. McGuire and colleagues from MedSeq: Integration of Whole Genome Sequencing into Clinical Medicine wrote a paper titled, “GINA, Genetic Discrimination and Genomic Medicine” that was published in the New England Journal of Medicine focusing on the Genetic Information Nondiscrimination Act (GINA). NEJM hosted an open forum where the authors and experts discussed GINA and genomic medicine in greater detail.

Mr. Adam Peña published an article in the American Journal of Bioethics, “Preventing the Predictable” that discusses emergent ethics consultation requested from the operating room.

Dr. Blumenthal-Barby also writes a monthly blog on bioethics.net that we encourage you to read.

RECOGNITION

Congratulations to Dr. Blumenthal-Barby for receiving the Fulbright & Jaworski L.L.P. Faculty Excellence Award in Educational Leadership and also being named a Distinguished Reviewer for the Journal of General Internal Medicine.

Congratulations to two Secondary Faculty members in the Center for their recent leadership appointments at Baylor College of Medicine. Dr. Mary Brandt was named the Associate Dean for Student Affairs and Dr. Joseph Kass was named the Assistant Dean for Student Affairs.

Congratulations to Mr. Adam Peña, M.A. who was recently promoted to the faculty rank of Instructor in the Center for Medical Ethics. Adam has played a important role in the coninued success and growth of our clinical ethics services at the Houston Methodist Hospital and the recognition is well deserved.

Congratulations to all!

In the News
Center faculty have provided commentary on a variety of controversial medical ethics cases garnering significant media attention.

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