

Baylor
College of
Medicine

CENTER FOR
MEDICAL ETHICS
& HEALTH POLICY



2019 ANNUAL REPORT

HUMANIZING BIG DATA AND HEALTHCARE

DIRECTOR'S CORNER

We are fast approaching 2020 and a new decade. Our world continues to move at a rapid pace, with technology increasingly integrated into what we do and who we are. And yet, it can often feel that healthcare is painfully slow, especially at critical moments—waiting for test results, frustrated by paperwork and policies, confused about how to navigate a complex and unfamiliar system.



These individual human experiences exist within a system that is imperfect, riddled with inequalities, inefficiencies, and perverse incentive structures. It is against this backdrop that there often is an unwillingness or uneasiness in asking the difficult ethics and policy questions.

The Center for Medical Ethics and Health Policy exists as a trusted partner to address these issues head-on.

We seek opportunities where physicians, patients and processes interact, to improve communications and positively influence how people think, feel, and behave.

The pages that follow outline key milestones and achievements in 2019. But beyond the numbers, we hope to give you a glimpse into the people and experiences that have impacted us directly.

Our achievements and activities over the past year are numerous and varied, but they each relate to a common theme of what we do, “humanizing big data and healthcare.” A key part of our job is to collect data, listen, and analyze. It’s the patients we see while doing hospital rounds as clinical ethics consultants, the people who take part in our research, and the students, residents, and healthcare providers we teach who inspire us and make our work meaningful.

Our goal is to help leverage what we learn from these individuals and apply it to the greater good—to create better research, improve patient-physician interactions, and move toward more humane and beneficial policies.

We are excited by what we’ve accomplished together this year. Thank you for your continued support, and rest assured we are just getting started!

A handwritten signature in black ink that reads "Amy McGuire".

Amy Lynn McGuire, J.D., Ph.D.

YEAR IN REVIEW

ETHICS AT THE BEDSIDE

IN 2019
WE CONDUCTED

600+

**CLINICAL ETHICS
CONSULTATIONS**

at Baylor St. Luke's
Medical Center and
Houston Methodist
Hospital.

We increased the number of patients and cases we took part in and helped reduce uncertainty and conflict in difficult situations. We served as a **resource** not only to patients and families, but also to physicians, nurses and other members of the healthcare team.

We worked with a wide range of hospital units (including cardiovascular intensive care, surgical intensive care, and nursing), stepping in at often the most critical and stressful times in a patient's journey. This involved interpreting advance directives, evaluating the proportionality of novel treatments, facilitating multidisciplinary team and family meetings, and mediating differences of opinion among medical providers, to name just a few.

Below is a recent case. Some facts have been changed to preserve anonymity, but this is the type of issue we frequently address.



✓ SAMPLE CLINICAL ETHICS CASE

Ms. Jones is a 60-year-old designer who told her primary care physician she wanted to “throw herself off a balcony.” The police were called, and she was admitted to the hospital under an emergency detention order (EDO). She verbally and physically resisted efforts to take medications orally and refused to be transported to the MRI suite. She stated repeatedly she wanted to leave the hospital. Psychiatry determined she lacked the decisional capacity to leave and refuse medications. The EDO will expire in 24 hours, and psychiatry does not plan to renew it.

Ms. Jones is not married. Her parents are deceased, and she has no children. Through conversations, the team uncovered she has a cousin in the area, a niece in a nearby state, and a friend who is a local dentist. Contact information is only available for the friend. Ms. Jones has an advance directive stating she would not want treatment (i.e. would want comfort care only) if she were in a terminal or irreversible condition. The directive also states that she has a medical power of attorney on file, but it was not in the chart.

Some Key Considerations:

Decision Making

- Should incapacitated patients be allowed to leave against medical advice in the absence of an EDO?
- If a surrogate decision maker is found and agrees to take her home, should Ms. Jones be permitted to leave? If a suitable surrogate decision maker isn't found, is it appropriate to ask a hospital representative or a chaplain to consent to provide medications over the patient's objections?
- What if a surrogate decision maker is found and refuses to consent to the recommended interventions?

Treatment

- What is the goal of providing treatment to Ms. Jones over her objections?
- What should the team do if Ms. Jones continues to refuse to take the recommended medications orally?
- If it would be ethically supportable to provide medications over her objections, what advice would you provide the team in order to minimize the potential for harm?
- What if the care team were divided regarding the ethical permissibility of using limited physical restraints in order to provide medications?

We have a profound understanding that Ms. Jones's experience is unimaginable and unforgettable to many. We approach every consult with a sense of responsibility, humility, urgency and compassion — to bring comfort to each patient and to help improve patient care in a way that positively impacts the overall system.

2020 AND BEYOND

Looking to the future, we will continue to enhance our efforts providing clinical ethics consultation to patients, families, and providers, allowing us to share our knowledge and experience and gain new insights. Because we work in the largest medical center in the world, we have a unique opportunity to address complex issues in a huge, diverse patient population and the potential to make transformational contributions to the field.

To that end, in early 2020 we will be hosting the second annual Clinical Ethics **UnConference** in partnership with Baylor St. Luke's Medical Center and Houston Methodist Hospital. It will provide a completely new approach to conferences that does not involve traditional didactic presentations. Building on the successful inaugural UnConference at the Cleveland Clinic in 2018, the 2020 Clinical Ethics UnConference will give participants an opportunity to contribute to the thinking and practice of medical ethics by exploring novel and unresolved issues in clinical ethics consultation.


 REGISTER [HERE](#) TO ATTEND!

Baylor
College of
Medicine

CENTER FOR
MEDICAL ETHICS
& HEALTH POLICY

EVOLVING CLINICAL ETHICS A Working UnConference

Feb. 5-7, 2020
Texas Medical Center
Houston



The UnConference will be a forum for practicing clinical ethicists to collaborate in moving our field forward. Professional clinical ethicists who lead clinical ethics programs or serve on ethics consultation services will benefit most from this meeting.

INFORMATION & REGISTRATION

bcm.edu/ethics/unconference
clinicaethics@bcm.edu 713.798.3500

IN PARTNERSHIP WITH ▶

Baylor St. Luke's Medical Center



HOUSTON
Methodist
LEADING MEDICINE

REWARDING RESEARCH

Our **research** continues to set a high standard to advance medical ethics and health policy.

We are one of the largest funded research programs of any bioethics program in the country, totaling over **\$3 million** in active research grants from premiere institutions such as the National Institutes of Health, the Patient-Centered Outcomes Research Institute, and the Greenwall Foundation.

In 2019 we published **50+** articles in leading journals such as *Nature Medicine*, *Science*, *Pediatrics*, *Nature Biotechnology*, *American Journal of Public Health*, *Health Affairs*, *Journal of the National Cancer Institute*, *Genetics in Medicine*, *Journal of Medical Ethics*, and *American Journal of Bioethics*. We explored issues such as newborn genomic sequencing, integrating genomics into psychiatric practice, lowering legal blood alcohol levels, and the HIPAA right of access to individuals' research data, among others.

Through our work we have been able to learn from stakeholders in medicine and biomedical research, including community representatives, delving deeply into important issues they face as individuals. Our questions span from intimate questions about day-to-day routines to deep philosophical goals and ethical challenges. These interactions impact us as people and allow us to learn from others' experiences to gain insights into policy and practice at every level.

Below is a tribute to one such patient-partner who contributed in important ways to our research; written by Jennifer Blumenthal-Barby, Ph.D., M.A. and her research team.



THE VALUE OF PATIENT PARTNERS

A Personal Perspective in Memoriam of Ms. Brenda Mays

"I have the perfect person for your project," a nurse coordinator said back in January 2014. We received funding for a study from the Patient-Centered Outcomes Research Institute (PCORI) to create a patient-centered decision aid about ventricular assist device (LVAD) placement in a clear, comprehensive, scientifically-valid, and unbiased manner to help patients make informed and value-based decisions.

Ms. Brenda Mays did turn out to be the perfect patient partner. She did the usual things a patient partner does—helped us think through research questions to ensure that we captured what mattered to patients, provided feedback on multiple versions of our decision aid, discussed timing to maximize its impact, and, once its effectiveness was established, helped inform other patients about this resource.

But Ms. Brenda did a lot more. She taught us the power of perseverance. Of positivity. Of fun. Of pure grit. Of warmth and openness. Of courage.

When we first met Brenda, she was already on her third LVAD. She laughed heartily and said, "I told Dr. X, the next time he cracks open my chest, he's going to have to give me a heart!" That was Brenda, always keeping things fun and lively.

Brenda's road with congestive heart failure was a long one, but she was brave. She overcame intense initial fear of the LVAD surgery to achieve her goals of moving around more easily and being out of breath less often. Brenda made this decision after talking to a patient who already had the device. That was also Brenda keeping herself informed and believing in the power of informing others. That's what motivated her to join our project—to inform other patients. She was so generous in sharing her story, her wisdom and perspective, and her friendship with us.

Ms. Brenda sadly passed away earlier this year. And while she is gone, she is certainly not forgotten. We are eternally grateful to her and all the other patients we get the honor and privilege of getting to know and who teach us the value of patient-partnered research.

2020 AND BEYOND

We are fortunate to work in a Center with a broad, diversified set of interests and grants to ensure our continued growth in 2020 and beyond. We were awarded several grants at the end of 2019, which are quickly getting off the ground in the areas of:



- Building effective ethical oversight for Citizen Science



- Helping neuro-oncologists navigate FDA expanded access



- The utility of risk information in Precision Medicine



- Decision-making preferences about clinical genome sequencing in adolescents and young adults



- The ethical and policy challenges with psychiatric polygenic risk scores in children and adolescents



- How to apply strategies of anticipatory governance to the management and control of human genome editing technologies



- Deep brain stimulation for the management of movement and psychiatric disorders in children

We're focused on the white space—uncovering areas in need of research or tools to help guide families and clinicians through difficult decision-making processes and inform policy making on complex issues. We're excited by what lies ahead and how we can advance biomedical research, improve patient care, and influence health and science policy by bringing forward new knowledge and ideas with a sense of urgency and purpose.

MEDICAL STUDENTS

Our two medical student educational pathways, **Medical Ethics** and **Health Policy**, continue to evolve to create a dynamic educational experience for students. We had a record 110 students in the Medical Ethics Pathway, the largest pathway in the college.

The final course for the Health Policy Pathway has been approved and will launch in March 2020. This innovative course will introduce students to major methodologies used in health policy analysis, prepare them for their capstone research project and bring students to immersion sites to experience health policy firsthand. Stephanie Morain, Ph.D., M.P.H, is newly appointed to direct the Health Policy Pathway and incorporate the latest health policy readings and findings. The Pathway continues to excel with 120 students registered in the 1st year Introduction to Health Policy elective and 20 students (course cap) enrolled in the 2nd year Seminar in Health Policy.

RESIDENTS

We officially launched an updated **Ethics, Professionalism and Policy Program (EP3)** to all 1,500 residents at BCM through the Learning Management System (LMS) in the new Success Factors platform. This is a significant milestone for the program and is the first time that the redesigned three-year curriculum is being deployed at the same time to all residents. This has required a major effort by our faculty and program staff. The first year of the curriculum includes five new modules:

- Professionalism in Practice
- Social Determinants of Health and Cultural Competency
- Effective Communication and Conflict Management
- Medical Errors
- Ethical Problem Solving

FELLOWS

We welcomed two new clinical ethics fellows



RYAN NELSON, PH.D.

Ryan completed his Ph.D. in Philosophy from the University of Utah.



BRYANNA MOORE, PH.D.

Bryanna completed a fellowship in pediatric bioethics from the Children's Mercy Hospital in Kansas. She has a Ph.D. in Philosophy from Monash University in Australia.

And one new health policy fellow



HADLEY STEVENS SMITH, PH.D.

Hadley got her M.P.A and B.S. from Texas A&M University and her Ph.D. from the University of Texas Health Science Center School of Public Health.

They join our existing clinical ethics fellow



JAMIE CRIST, J.D., M.A.

Jamie attended Case Western Reserve University, where she earned a J.D. and a M.A. in Bioethics.

Below is a recent example of how our teaching isn't a one-size-fits-all approach. We are constantly evolving our practices, people and processes, and that impacts not only how we teach, but also what and who we learn and grow from.

AN INTERN'S IMPACT: *Navigating requests for experimental medicines*

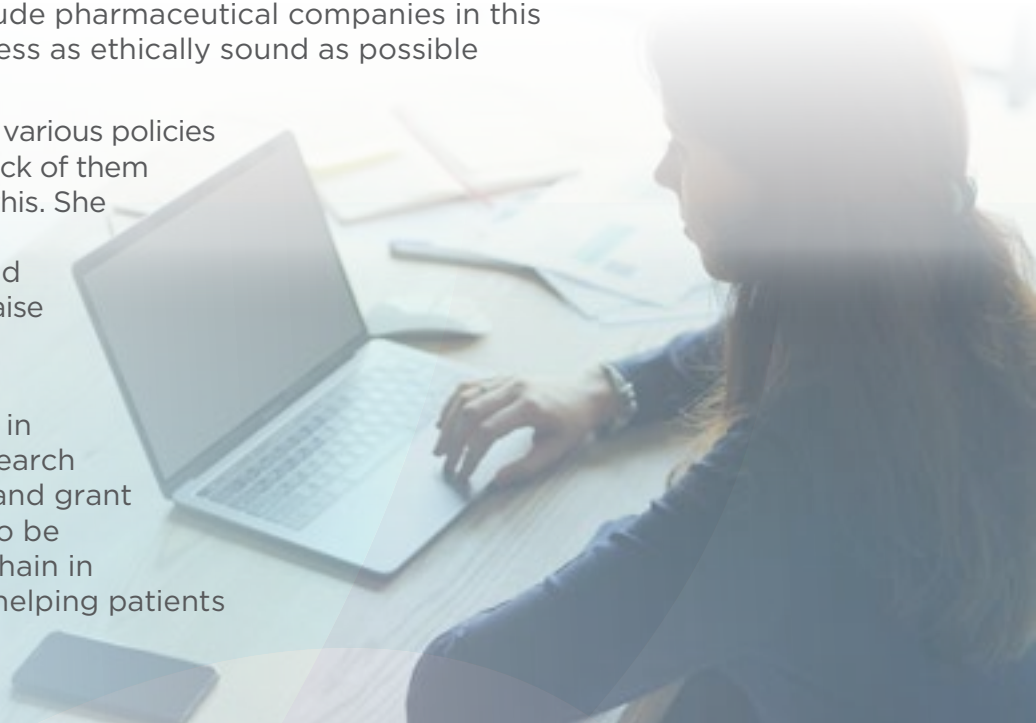
We know the old stereotypes: interns get coffee and make photocopies. But here's an example of a true self-starter who added not only depth to our research literature, but also substance.

Hannah came to us through **The Health, Humanism, and Society Scholars** program (HHASS), which provides Rice undergraduates the opportunity to assist in research at various institutions in the Texas Medical Center. Like many from this program, from day one it was clear she was bright and motivated. But what really made her stand out was her ideas and her initiative.

The research team she worked with focuses on the physician's ethical obligations and looks to provide guidance on helping individuals with life-threatening illness access investigational drugs that have not yet received approval from the Food and Drug Administration (FDA). Hannah's father is a pharmaceutical executive so she had inherent knowledge about how drug companies and insurance providers participate in making experimental treatments accessible to those who need them by being the gatekeepers. That perspective helped our project immensely. She expanded our thinking to include pharmaceutical companies in this guidance, trying to make the process as ethically sound as possible from all sides.

Furthermore, she helped us identify various policies (hospital, medical centers, etc.) or lack of them and what doctors should do about this. She became an expert in the landscape, reading every article on the topic and during meetings would frequently raise her hand citing recent legislation or documents.

In the end, while we mentored her in the process of ethical analysis, research methods, interviewing and paper and grant writing, she expanded our scope to be more inclusive across the supply chain in an effort to improve the ethics of helping patients access treatment.



HONORING OUR FOUNDER *and the FUTURE*

This year, we will inaugurate the **Baruch A. Brody Lecture**, which includes a \$10,000 award and lecture to perpetuate our late founder's legacy by recognizing a junior or mid-career scholar who has made important contributions to the field of bioethics. We partnered with Houston Methodist Hospital and the Rice University Department of Philosophy to establish the lectureship and award. We are thrilled to honor **Holly Fernandez Lynch, J.D., M.Be.**, of Perelman School of Medicine, University of Pennsylvania. The award presentation and inaugural lecture will take place on Wednesday, Feb. 5, at 5 p.m. at the Houston Methodist Research Institute (HMRI) Auditorium in Houston, Texas, as part of the **2nd Clinical Ethics UnConference**.



For remote access: <https://bcm.zoom.us/j/249346811>

To Register Dial: 281.824.3734 and enter Event ID: 36109

2020 AND BEYOND

As we look ahead, we have several upcoming events where we will bring people together to share our knowledge and know-how:

GRAND ROUNDS - MONTHLY

We hold these frequently at Houston Methodist Hospital and Baylor St. Luke's Medical Center for healthcare professionals, but they are open to anyone interested in attending. Dates, times and speakers for 2020 are still being determined but likely topics include:

- interfaith panel discussion on religion and ethics in organ donation
 - opioids and ethics
 - immigration care
 - the new ethics of disclosure of HIV status
 - evidence and ethics in gender-affirming interventions
 - the new role for AI as a medical decision-maker
- ▶ Check our [website](#) for updates and remote access in some cases.

BIOETHICS INTENSIVE COURSE

📅 **April 20-24, 2020**

In partnership with Houston Methodist, we offer a five-day course in the Texas Medical Center designed to help participants develop core competencies and integrate innovations in their clinical ethics consultation practice.

▶ Learn more [here](#).

HEALTH POLICY DAY

📅 **May 27, 2020**

Our second annual event where 16 Faculty present/discuss contemporary challenges in health policy (topics such as how technology is changing healthcare and where to draw the line, protecting privacy in the era of precision medicine and learning health systems, and the role of healthcare providers and professionals in policy and advocacy, to name a few). It will be an engaging event reaching people throughout the Texas Medical Center.

▶ [Learn more and register today](#)



SHARING OUR PERSPECTIVE

2019 PUBLICATION HIGHLIGHTS

In 2019 we dialed up our ongoing focus on media and stakeholder engagement to increase visibility, attention and action on issues we care about. We hope to continue this effort in the year ahead to cement our presence and continue to have an impact.

- 50+ **media mentions** in outlets such as *NBC News*, *Washington Post*, *The Atlantic*, *STAT*, *Bloomberg*, and *Los Angeles Times*
- Developed Baylor's first-ever **policy position paper** (on the measles outbreak), followed by another one on **youth smoking and vaping**; we have several more in development.
- Held inaugural Health & Science Policy Research Day with 100+ attendees from across the TMC
- Published 45+ **blog posts**, receiving thousands of views

2019 PUBLICATION HIGHLIGHTS

 <p>Ethical Argument to Lowering Legal Blood Alcohol Levels</p>	 <p>We Don't Need Unilateral DNRs: Taking Informed Non-Dissent One Step Further</p>	 <p>Challenging the Current Recommendations for Carrier Testing in Children</p>
 <p>Oposing Effects of Neurobiological Evidence on Criminal Sentencing Judgments</p>	 <p>Regulating Genetic Biohacking</p>	 <p>Alienation, Quality of Life, and DBS for Depression</p>
 <p>Potential Unintended Consequences Of Recent Shared Decision Making Policy Initiatives</p>	 <p>Clarifying the HIPAA Right of Access to Individuals' Research Data</p>	 <p>In Support of Mitochondrial Replacement Therapy</p>

2019 MEDIA HIGHLIGHTS

 <p>Let's Change the Rules for Organ Donation - and Save Lives</p>	 <p>Huge US Government Study to Offer Genetic Counseling</p>	 <p>What a Fellowship Is and Why You Might Want One</p>
 <p>Why You Should File a Health Care Proxy Form ASAP</p>	 <p>DNA Company Wants You to Help Catch Criminals</p>	 <p>Texas Legislature Hikes Age for Tobacco Use from 18 to 21</p>
 <p>Tinder for Clinical Trials</p>	 <p>Beyond Cadavers: Med Students Learn to Dissect Health Policy</p>	 <p>Police Were Cracking Cold Cases With a DNA Website. Then the Fine Print Changed.</p>

JOIN US!

DONATE

Help support our mission of conducting innovative multidisciplinary research on ethical issues arising in clinical practice and biomedical research. This research informs the education of trainees at all levels and contributes to the development of health policy at the local, national, and international levels. If you're interested in learning more, [click here](#) or please contact the Office of Institutional Advancement and Alumni Relations at ☎713.798.4714.

CONNECT & GET INVOLVED

Follow us on Twitter @[BCMEthics](#), like us on [Facebook](#) and read our [Blog](#). Check out our upcoming events. [Subscribe to our mailing list](#) to stay updated on the latest developments.



Baylor
College of
Medicine

CENTER FOR
MEDICAL ETHICS
& HEALTH POLICY

BCM.EDU/ETHICS