

Harvard Medical School Center for Bioethics

HARVARD CLINICAL BIOETHICS COURSE

JUNE 6-8, 2018



**CENTER FOR
BIOETHICS**
HARVARD MEDICAL SCHOOL



Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.

—Margaret Mead



Harvard Medical School Center for Bioethics Administration

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2018 Harvard Clinical Bioethics Course

A Message from the Course Directors



Welcome to the Harvard Clinical Bioethics Course. We are delighted that you are joining us here at Harvard Medical School, but we are even more pleased that your attendance reflects a serious commitment to ethics in biomedicine.

Harvard Medical School launched the Center for Bioethics out of the conviction

that we—as care providers, educators, and researchers—have a particular responsibility to ensure that values and ethics are always part of medical training, laboratory and clinical research, and ongoing professional education.

This course will provide a foundational understanding of ethical theories and methods related to issues in clinical care. Together, we will explore the standards for ethics consultation, as well as areas of ethical controversy and consensus. Members of clinical ethics committees, organizational ethics task forces and ethics consultation services—and those who are *preparing* to serve on ethics committees or provide ethics consults—will find this theoretical primer and ethical analysis of clinical cases particularly useful.

This year, the agenda includes a dynamic combination of lectures, case discussions, and smaller sessions focusing on existing ethical controversies in clinical care and anticipating new ones. Our goal is to enhance each participant's competence to recognize, analyze, and address ethical issues in health care.

Professionals from a wide variety of fields—from physicians to chaplains, nurses to human rights officers, social workers to surgeons, hospital attorneys and trustees—will find this course of value. Small group discussion and concurrent sessions are designed to enable participants to choose sessions according to their interests.

Course instructors are drawn from Harvard Medical School and its affiliated hospitals and institutions. These faculty members are published experts in the specialty areas in which they teach, including bioethics, moral philosophy, medicine, and health care.

We hope that everyone will find something of value, and that you will tell professionals in your field and others who may be interested in learning about this course. If you have ideas or suggestions for how we can improve, please be in touch.

Rapid advances in modern medicine are making this already ethically challenging field even more complex. Now, more than ever, biomedicine needs leaders who are able to anticipate and identify moral issues related to health and who can engage in skilled bioethical decision-making. Thank you for coming to meet the challenge with us.

Christine Mitchell, RN, MS, MTS
Executive Director

Robert Truog, MD, MA
Director

The Center for Bioethics at Harvard Medical School

The Center for Bioethics at Harvard Medical School is founded on the principle that we have a responsibility to ensure values and ethics are always part of medical training, clinical practice, laboratory and clinical research, and ongoing professional education.

The Center hosts monthly consortia, a current authors and speakers series and other topical talks and events for health professionals, faculty and administrators to collaborate on the most pressing bioethical challenges of our time in the hope of making health systems, professional organizations, and individuals more responsive to the communities served.

Through the master of bioethics degree, fellowship in bioethics, postdoctoral research scholars program, and conferences, the Center prepares professionals to address the profound moral questions raised by advances in the life sciences.

For more information, see bioethics.hms.harvard.edu



WED

SCHEDULE OF EVENTS



Wednesday, June 6, 2018*

Time	Session	Location*
8:00 am	Registration and Breakfast	TMEC Atrium
8:30 am	Welcome	TMEC Amphitheater
8:45 am	Clinical Bioethics: Connecting Theory with Practice	
9:30 am	Participant-Faculty Discussion	
9:45 am	Moral Reasoning: Philosophy and Clinical Bioethics	
10:30 am	Participant-Faculty Discussion	
10:45 am	Refreshment Break	TMEC Atrium
11:00 am	Medical Futility	
11:45 am	Participant-Faculty Discussion	
Noon	Transition to Working Lunch	Pick up tote lunch in TMEC Atrium
12:15 pm	Working Lunch: Small Group Case Discussion (See "A Mother's Death" on page 47)	Room assigned at registration
1:30 pm	Transition Break	
1:45 pm	Disorders of Consciousness and Ethical Issues	
2:30 pm	Participant-Faculty Discussion	
2:45 pm	Refreshment Break and Transition to Concurrent Sessions	TMEC Atrium
3:00 pm	▼ Concurrent Sessions	
	Advance Care Planning	TMEC 106
	Values, Uncertainty, and Counseling in Prenatal Decisions	TMEC L-008
	The Surgical Learning Curve	TMEC L-007
	Healthcare Rationing and Distributive Justice	TMEC 128
	Neuroethics	TMEC 306
	Human Rights in Health and Science	TMEC 328
4:00 pm	Transition Break to Concurrent Sessions	
4:15 pm	▼ Concurrent Sessions	
	Advance Care Planning	TMEC 106
	Values, Uncertainty, and Counseling in Prenatal Decisions	TMEC L-008
	The Surgical Learning Curve	TMEC L-007
	Healthcare Rationing and Distributive Justice	TMEC 128
	Neuroethics	TMEC 306
	Human Rights in Health and Science	TMEC 328
5:15 pm	Networking Reception	TMEC Atrium
6:00 pm	Panel: Addressing LGBTQ Concerns in Health Care	

*All sessions will be held in the TMEC Amphitheater unless otherwise noted.

Wednesday, June 6, 2018*

8:00 am Registration and Breakfast

8:30 am Welcome

8:45 am

Clinical Bioethics: Connecting Theory with Practice

Christine Mitchell, RN, MS, MTS

Why do we have clinical ethics committees in health care?

Learning Objectives:

- Identify key events in the historical development of clinical bioethics
- Discuss the purposes and evolution of clinical bioethics
- Distinguish types of ethical theories
- Explore links between ethical theory and practice

9:30 am Participant-Faculty Discussion

9:45 am

Moral Reasoning: Philosophy and Clinical Bioethics

Andrew Schroeder, PhD

Are we born with ethical wisdom? Does it come through life experience? Or can it be learned in a classroom? In this session, I will suggest that the third option is at least part of the story. We will talk about how clinicians can benefit from studying bioethics, and how academic philosophy in particular can aid in making difficult ethical decisions. We will conclude by laying out two methods of moral reasoning, and applying them to a pair of cases.

Learning Objectives:

- Identify the many "hidden" ethical dimensions of clinical work
- Describe how studying bioethics and philosophy can aid in ethical decision-making
- Identify the limits of philosophical methods
- Apply two methods of moral reasoning

10:30 am Participant-Faculty Discussion

10:45 am Refreshment Break

11:00 am**Medical Futility***Robert Truog, MD, MA*

Deciding when the use of life-sustaining treatment has become “futile” is the top issue faced by hospital ethics committees in the United States today. In this session we will explore the various meanings of the concept of futility and current efforts to resolve these dilemmas.

Learning Objectives:

- Describe what we mean when we say that medical futility is a debate about “odds and ends”
- Based on the data described in the lecture, assess whether futility guidelines are likely to be effective in decreasing the cost of healthcare
- Discuss the ethical pros and cons of the Texas futility legislation

11:45 am Participant-Faculty Discussion**Noon Transition to Working Lunch** (pick up tote lunch in the TMEC Atrium)**12:15 pm****Working Lunch: Small Group Case Discussion**

(See page 47 for “A Mother's Death.” Rooms assigned at registration.)

1:30 pm Transition to TMEC Amphitheater**1:45 pm****Disorders of Consciousness and Ethical Issues***Thomas Cochrane, MD, MBA*

Ethics consultants and clinicians are frequently called upon to make decisions about life-sustaining therapy for patients with severe disorders of consciousness. Some basic neurology as pertains to disordered consciousness will be covered, as will the ethical principles guiding decision-making in this context.

Learning Objectives:

- Define diagnostic categories such as brain death, vegetative state, coma, and minimally conscious state
- Identify the ethical principles that guide decision-making regarding life sustaining therapy for patients with disordered consciousness

***All sessions will be held in the TMEC Amphitheater unless otherwise noted.**

Wednesday, June 6, 2018*

2:30 pm Participant-Faculty Discussion

2:45 pm Coffee and Transition Break

3:00 pm Concurrent Sessions

Advance Care Planning | TMEC 106

David Sontag, JD, MBE, and Carol Powers, JD

This session will explore the ethical foundations underlying the need for advance care planning and will examine the practical implications of effective and ineffective advance care planning. The session will provide strategies for engaging in discussions with patients about this sensitive, but critically important topic.

Learning Objectives:

- Describe the importance of advance care planning, from both ethical and practical perspectives
- Discuss strategies to elicit and understand a patient's wishes, even when the patient cannot speak for herself

Values, Uncertainty, and Counseling in Prenatal Decisions | TMEC L-008

Stephen Brown, MD

Providers of prenatal counseling face chronic exposure to emotionally and ethically delicate decisions. Clinical ambiguity and prognostic uncertainty are inherent to prenatal management decisions, particularly when a fetal abnormality is diagnosed. Cultural pressures and social expectations are deeply embedded into the decision-making process. This session uses videotaped prenatal counseling simulations comparing and contrasting counseling processes after unexpected diagnoses of first trimester miscarriage and second trimester fetal spina bifida as a framework for examining how values, uncertainty, and social morays may affect the dynamics of difficult prenatal conversations.

Learning Objectives:

- Analyze the presence and effect of micro-ethical values that may be embedded in prenatal conversations
- Discuss how prognostic and diagnostic certainty and uncertainty influence the tenor of prenatal counseling
- Appraise the impact of social morays on counseling, emotional processing and decision-making during difficult and unexpected prenatal diagnoses

*All sessions will be held in the TMEC Amphitheater unless otherwise noted.

Concurrent Sessions, continued

The Surgical Learning Curve | TMEC L-007

John Mayer, MD

This session addresses the bioethics considerations involved in the introduction of innovative surgical therapies into the clinical setting. The background for this discussion is the dual professional responsibilities of a physician to be both a “healer of the sick” and a member of the medical profession with duties to advance and disseminate knowledge. Discussion will be based, in part, on a case involving a new operative approach with unknown outcomes to a highly lethal disease process to replace an existing, accepted procedure with good early results but serious problems that occur years.

Learning Objectives:

- Discuss the concepts of innovation and learning
- Describe the ethical issues involved in the surgical learning curve including the surgeon’s responsibilities to the patient and to society as a whole
- Describe the potential pitfalls for the individual surgeon and the institution in which the innovation occurs
- Discuss models of institutional review of innovative surgical therapies

Healthcare Rationing and Distributive Justice | TMEC 128

Andrew Schroeder, PhD

This session will show the necessity of some form of rationing; expose attendees to some philosophical theories of distributive justice; show how those theories can be used in healthcare contexts; emphasize the difference between procedure-based and distribution-based approaches; and offer practical advice on how attendees can approach situations in which resources are limited.

Learning Objectives:

- Identify selected philosophical theories of distributive justice used in health care contexts
- Describe the difference between procedure-based and distribution-based approaches
- Provide practical advice on how attendees can approach situations in which resources are limited

Wednesday, June 6, 2018*

Concurrent Sessions, continued

Neuroethics | TMEC 306

Laura Specker Sullivan, PhD

This session begins with a review of the history of neuroethics and different forms of neuroethics research. Core technologies (e.g., SSRIs, DBS, BCI, enhancement) and concepts (e.g., consciousness, identity, agency, responsibility, normality) are described. Salient clinical cases are used to illustrate common neuroethical issues and situations.

Learning Objectives:

- Summarize the history of neuroethics and its two branches
- Describe the ethical significance and use of core technologies
- Explain the meaning of salient ethical concepts
- Assess paradigm cases of neuroethics analysis

Human Rights in Health and Science | TMEC 328

Wes Boyd, MD, PhD, and Emily Keehn, JD

This session will examine issues pertaining to health and science in the context of human rights. Questions addressed include: If we have a right to health, does that include the right to health care and/or the right to receive medications? If so, what are some of the systematic obstacles to actually obtaining needed care? How can research on certain populations—for example, those who are incarcerated—be carried out in an ethical manner? In examining these questions we will focus on certain vulnerable populations.

Learning Objectives:

- Understand critical issues at the intersection of health, science, and human rights, including the potential tension between individual rights versus the public good
- Ascertain some of the ethical issues pertaining to women's health and reproductive rights
- Explore the ways in which human rights can address health issues that severely impact marginalized groups, such as incarcerated people and others in conflict with the law, and the ways in which disease and ill health in turn impede the realization of a range of human rights
- Discuss the ways in which scientific inquiry could be used to foster protections of human rights and also the ways in which scientific findings might be used to adversely affect certain vulnerable populations

4:00 pm Transition Break to Concurrent Sessions

*All sessions will be held in the TMEC Amphitheater unless otherwise noted.

4:15 pm **Concurrent Sessions** (see pages 8-10 for descriptions of sessions)

Advance Care Planning | **TMEC 106**

David Sontag, JD, MBE, and Carol Powers, JD

Values, Uncertainty, and Counseling in Prenatal Decisions | **TMEC L-008**

Stephen Brown, MD

The Surgical Learning Curve | **TMEC L-007**

John Mayer, MD

Healthcare Rationing and Distributive Justice | **TMEC 128**

Andrew Schroeder, PhD

Neuroethics | **TMEC 306**

Laura Specker Sullivan, PhD

Human Rights in Health and Science | **TMEC 328**

Wes Boyd, MD, PhD and Emily Keehn, JD

5:15 pm **Networking Reception**

6:00 pm

Panel Discussion: Addressing LGBTQ Concerns in Health Care

THURS

SCHEDULE OF EVENTS



Thursday, June 7, 2018*

Time	Session	Location*
8:00 am	Registration and Breakfast	TMEC Atrium
8:30 am	Clinical Ethics Consultation: Standards and Strategies	TMEC Amphitheater
9:10 am	Participant-Faculty Discussion	
9:30 am	▼ Approaches to Ethical Analysis	
	Principlism	
9:45 am	Casualty	
10:00 am	Virtue Ethics	
10:15 am	Participant-Faculty Discussion	
10:30 am	Break	
10:45 am	Feminist Ethics	
11:00 am	Utilitarianism	
11:15 am	Narrative Ethics	
11:30 am	Participant-Faculty Discussion	
Noon	Transition to Working Lunch	Pick up tote lunch in TMEC Atrium
12:15 pm	Working Lunch: Small Group Case Discussion (See "Jamie's Story" on page 48)	Rooms assigned at registration
1:15 pm	Transition to TMEC Amphitheater	
1:30 pm	Teaching Bioethics: Practical Approaches to Common Challenges	
2:00 pm	Participant-Faculty Discussion	
2:10 pm	▼ Transition to Concurrent Sessions	
2:15	Defining Death and Organ Transplantation	TMEC 306
	Spirituality, Religion, and Clinical Ethics	TMEC 328
	Public Reporting of Surgical Outcomes	TMEC L-008
	Organizational Ethics in a Changing Hospital Policy Environment	TMEC 128
	Talking to Families about Ethics Consultation: A Video	TMEC 106
	Tips and Problems in Ethics Consultation	TMEC 209
3:15 pm	Transition to Concurrent Sessions	
3:30 pm	▼ Concurrent Sessions	
	Defining Death and Organ Transplantation	TMEC 306
	Spirituality, Religion, and Clinical Ethics	TMEC 328
	Public Reporting of Surgical Outcomes	TMEC L-008
	Organizational Ethics in a Changing Hospital Policy Environment	TMEC 128
	Talking to Families about Ethics Consultation: A Video	TMEC 106
	Tips and Problems in Ethics Consultation	TMEC 209
4:20 pm	Transition to TMEC Amphitheater	
4:30 pm	When Things Go Wrong: Talking with Patients after Medical Mistakes	
5:15 pm	Participant-Faculty Discussion	
5:30 pm	Networking Reception	TMEC Atrium
6:15 pm	Bioethics and Genomics: Center Stage - A Play	

*All sessions will be held in the TMEC Amphitheater unless otherwise noted.

Thursday, June 7, 2018*

8:00 am Registration and Breakfast**8:30 am****Clinical Ethics Consultation: Standards and Strategies***Christine Mitchell, RN, MS, MTS*

This session will identify the goals of ethics consultation and explore the process and components of the consultation activities. We will review the developments and standards in the field of ethics consultation, including attestation of competence of ethics consultants and the code of ethics for consultants.

Learning Objectives:

- Identify goals of ethics consultation
- Describe processes of ethics consultation
- Review developments in field of ethics consultation

9:10 am Participant-Faculty Discussion**Approaches to Ethical Analysis****9:30 am** Principlism*Laura Specker Sullivan, PhD*

Many moral philosophers and bioethicists have stressed the importance of moral principles in ethical analysis. A central feature of doing bioethics well is properly applying these principles to actions, decisions, dispositions, and states of affairs. This session provides a broad overview of an approach to bioethics methodology known as principlism, highlighting briefly its application, strengths, and limitations.

Learning Objectives:

- Understand a principlist approach to bioethics methodology
- Identify the necessity of principles for ethical analysis
- Appreciate the limitations of principles in ethical analysis

*All sessions will be held in the TMEC Amphitheater unless otherwise noted.

Approaches to Ethical Analysis, continued**9:45 am Casuistry***Patrick Smith, PhD*

A method of analogical moral reasoning that focuses on applying rules drawn from paradigmatic cases to new cases with relevant similarities.

Learning Objectives:

- Describe the process of casuistic reasoning
- Identify limitations of casuistry

10 :00 am Virtue Ethics*Rebecca Weintraub Brendel, MD, JD*

This session will provide an overview of the key features of virtue ethics theory from Aristotelian conceptions to contemporary relevance to bioethics. This brief session will engage the central focus of virtue ethics on qualities of the moral actor as opposed to rules of conduct encountered in competing moral theories. The presentation will conclude with an assessment of some of the strengths and weaknesses of virtue ethics for bioethics inquiry.

Learning Objectives:

- Understand the main features of virtue ethics
- Appreciate virtue ethics as a distinct normative theory
- Identify the strengths and weaknesses of virtue ethics for bioethics

10:15 am Participant-Faculty Discussion**10:30am Break**

Thursday, June 7, 2018*

Approaches to Ethical Analysis, continued

10:45 am Feminist Ethics

Charlene Galarneau, PhD

This session begins with a brief history of feminist bioethics and the reasons for its emergence. Relevant terms (gender, intersectionality, power/oppression/privilege, justice) and core concepts (relational autonomy, standpoint theory) are described. Elements of feminist analysis are outlined and their implications for models of clinical consultation are illustrated.

Learning Objectives:

- Summarize the reasons for the historical emergence of feminist bioethics
- Describe central terms and concepts in feminist bioethics
- Recognize gender relations at work in clinical settings
- Assess a clinical ethics case cognizant of gender and other power relations

11:00 am Utilitarianism

Andrew Schroeder, PhD

This brief session will introduce the ethical theories of utilitarianism and consequentialism, and will show how they can be applied to a medical case.

Learning Objectives:

- Understand the theories of utilitarianism and consequentialism.
- Identify medical cases in which their use may seem appropriate.
- Identify medical cases in which their use may seem problematic.

11:15 am Narrative Ethics

Charlotte Harrison, PhD, JD, MPH, MTS

This session will introduce characteristics of narrative ethics, methodology, and will provide case examples

Learning Objectives:

- Discuss and make use of narrative approaches to clinical ethics

11:30 am Participant-Faculty Discussion

Noon Transition to Working Lunch (pick up bag lunch in the TMEC Atrium)

12:15 pm Working Lunch: Small Group Case Discussion

(See page 48 for "Jamie's Story." Rooms assigned at registration.)

*All sessions will be held in the TMEC Amphitheater unless otherwise noted.

1:15 pm Transition to TMEC Amphitheater**1:30 pm** Teaching Bioethics: Practical Approaches to Common Challenges*Edward Hundert, MD*

This session will offer participants a chance to identify and discuss the pros and cons of the fundamental tradeoffs that bioethics teachers face in designing and implementing clinical ethics education programs. Approaches that have been tried at Harvard Medical School will be shared, and all participants will be invited to reflect on how to apply lessons learned to their own unique institutional settings.

Learning Objectives:

- Choose the best format, pedagogy, and content for bioethics teaching and learning
- Describe the challenges of teaching how to think, more than what to think, about bioethics
- Discuss ways to make bioethics teaching relevant, meaningful, and enjoyable

2:00 pm Participant-Faculty Discussion**2:10 pm** Transition to Concurrent Sessions**2:15 pm** Concurrent Sessions

Defining Death and Organ Transplantation | TMEC 306

Robert Truog, MD, MA

This session will review the history and conceptual foundations of our definitions of death, and discuss their relationship to current approaches to organ donation. Evidence that challenges the current paradigm will be presented, as well as an outline of possible alternatives for framing the ethics of organ donation.

Learning Objectives:

- Describe the criteria used to diagnose brain death, and give one type of evidence that critics have used to question the validity of the concept
- Describe the criteria used to diagnose circulatory death, and give one type of evidence that critics have used to question the validity of the concept
- Describe the “dead-donor rule,” and give your opinion about whether it should remain a foundational principle in the ethics of organ donation

Thursday, June 7, 2018*

Concurrent Sessions, continued

Spirituality, Religion, and Clinical Ethics: Some Contributions and Challenges | TMEC 328

Patrick Smith, PhD, and Michael Balboni, PhD, ThM, MDiv

For good or ill, spiritual, theological, and religious resources have played significant roles in health care and clinical ethics. Historically, health care has been associated with religious communities and partially shaped by some of the values that emerge from these traditions. Many patients and their families who interface with the scientific medical community along with a number of health care professionals have been influenced by these traditions and the mixed set of values embraced within them. The insights from these resources and the data surrounding the role of spirituality in health outcomes can contribute to a better understanding and engagement with representatives from these traditions in clinical spaces. This workshop identifies some contributions and challenges that spirituality, religion, and theological perspectives can have in the clinical ethics encounter.

Learning Objectives:

- Describe empirical studies that establish: (i) the beneficial patient health outcomes of attention to spiritual care from clinicians, (ii) the role of spirituality and religion in patient end of life decision-making, and (iii) that spiritual encounters rarely take place in patient physician relationship
- Identify some of the challenges associated with the encounter of clinical ethics, spirituality, and religion
- Imagine more constructive relationships between of religion and medicine in clinical spaces

Public Reporting of Surgical Outcomes | TMEC L-008

Richard Whyte, MD, MBA

This session will address potential methodological and ethical issues concerning what, on the surface, appears to be a laudable goal.

Learning Objectives:

- Recognize the shortcomings of publicly reported surgical outcomes data
- Discuss how current publicly reported outcomes data may be misleading to a lay audience
- Describe how the initial goal of surgical quality databases; ie. quality improvement, may be corrupted by competition and marketing
- Understand how volume targets alone may have unintended results in terms of access to care

*All sessions will be held in the TMEC Amphitheater unless otherwise noted.

Concurrent Sessions, continued

Organizational Ethics in a Changing Hospital Policy Environment: What's a Hospital To Do? | TMEC 128

Lauren Taylor, MPH, MDiv

This session explores the ethical dilemmas posed by health care organizations' transition from fee-for-service to value-based care, specifically addressing the social determinants of health. Challenges at both the managerial and clinical levels are raised and explored.

Learning Objectives:

- Describe how current health policies (ACA, AHCA, state Medicaid redesigns) influence the development of new business models
- Identify ethical dilemmas faced by managers and providers in implementing new business models

Talking to Families about Ethics Consultation: A Video | TMEC 106

Martha Jurchak, PhD, and Wendy McHugh, RN, MS

How do you introduce families to an ethics consultation? How do ethics consultants engage families in ethics consultation, especially when the family may not have requested the ethics consult? Using video simulations, this session offers various approaches that ethics consultants use in approaching families regarding an ethics consultation, and the benefits and shortcomings of these approaches.

Learning Objectives:

- Identify the important components of ethics consultation introduction
- Describe the skills, knowledge, and process that promote ethics consultation engagement

Thursday, June 7, 2018*

Concurrent Sessions, continued

Tips and Problems in Ethics Consultation | TMEC 209

Christine Mitchell, RN, MS, MTS

Ethics consults in health care facilities are often requested after other efforts to solve a conflict have not worked, feelings are hurt, and positions have hardened. How should an ethics consult team (or consultant) facilitate moral uncertainties, value conflicts, and ethical disagreements? What authority do ethics consultants have? What hazards do ethics consultants face? And what strategies have ethics consultants found effective to handle moral distress, deal with tragic choices, and enable people to make ethical agreements and compromises.

Learning Objectives:

- Discuss tensions in dealing with moral values and feelings among various participants in clinical ethical decisions
- Provide tips for doing effective ethical consultations
- Identify and discuss problems that come up in ethics consults, besides the ethical issues

3:15 pm Transition to Concurrent Sessions

3:20 pm Concurrent Sessions (see pages 18-19 for descriptions of sessions)

Defining Death and Organ Transplantation | TMEC 306

Robert Truog, MD, MA

Religious Contributions in Clinical Ethics | TMEC 328

Patrick Smith, PhD, and Michael Balboni, PhD, ThM, MDiv

Public Reporting of Surgical Outcomes | TMEC L-008

Richard Whyte, MD, MBA

Organizational Ethics in a Changing Hospital Policy Environment: What's a Hospital To Do? | TMEC 128

Lauren Taylor, MPH, MDiv

*All sessions will be held in the TMEC Amphitheater unless otherwise noted.

Concurrent Sessions, continued

Talking to Families about Ethics Consultation - A Video | TMEC 106

Martha Jurchak, PhD, and Wendy McHugh, RN, MS

Tips and Problems in Ethics Consultation | TMEC 209

Christine Mitchell, RN, MS, MTS

4:15 pm Transition to TMEC Amphitheater

4:30 pm

When Things Go Wrong: Talking with Patients after Medical Mistakes

Robert Truog, MD, MA

Until fairly recently, clinicians were routinely told never to admit to a medical error. But patients and society have come to expect and demand more openness and transparency around adverse events and errors, and the medical profession is slowly changing its approach. Not only is an honest approach “the right thing to do,” but it has other benefits as well, such as assuring that errors are analyzed and steps taken to reduce the risk of them happening again. In addition, we have learned that empathic disclosure of errors may actually decrease the risk of malpractice litigation, making it possible for patients to be justly compensated for errors without the need to embark upon the costly process of litigation.

Learning Objectives:

- Contrast the change in attitudes about disclosure of medical error over the past 10 years with the much slower evolution in actual practice, the so-called “disclosure gap”
- Provide evidence in favor of the view that improved disclosure will save money, as well as evidence that it may significantly increase costs
- Discuss recommendations about the threshold for disclosing medical errors and appropriate use of the words “I’m sorry”

5:15 pm Participant-Faculty Discussion

5:30 pm Networking Reception

Thursday, June 7, 2018*

Concurrent Sessions, continued

6:15 pm

Bioethics and Genomics: Center Stage—A Play

Playwright: *Lynn Bush, PhD, MA*

Moderator: *Rebecca Weintraub Brendel, MD, JD*

Actors: *Wes Boyd, MD, PhD; Louise King, MD, JD; David Urion, MD*

The ethical complexities and implications of applying genomic technologies in prenatal, neonatal, and pediatric settings take center stage, providing the inspiration and drama for a new vignette-play. This interactive journey begins with a semi-fictionalized case-based drama situated on a thorny landscape of ethical, psychological, and policy challenges at medical centers today. The characters' dialogue illuminates the important role of bioethicists in helping healthcare providers critically examine the significance of contextual variation, such as managing uncertainty and balancing diverse perspectives amongst families and inter-professionally. The play sets the stage to enhance reflective ethical consideration and foster lively interdisciplinary discourse. After the performance, a panel of course faculty with particular expertise in subject matter covered in the play will explore and share insights regarding the ethical issues raised in the play—processes of decision-making, counseling, informed consent, and return of genomic findings—then engage the audience in further conversation

Learning Objectives:

- Recognize the important role of bioethicists integrated in clinical departments to help healthcare providers better appreciate and navigate ethical complexities and implications when genomic technologies are applied in prenatal, neonatal, and pediatric settings.
- Differentiate the ethical, psychosocial, and policy challenges to professionals and patients in order to be flexible when faced with explaining and managing genomic uncertainty.
- Integrate creative pedagogical approaches as a bioethics teaching tool to facilitate inter-professional exploration and discourse on challenging ethical and psychological issues, especially involving decision-making.

*All sessions will be held in the TMEC Amphitheater unless otherwise noted.

[illegible]

FRIDAY

SCHEDULE OF EVENTS



Friday, June 8, 2018*

Time	Session	Location*
8:00 am	Breakfast	TMEC Atrium
8:30 am	Ethical Issues in Women's Health and Assisted Reproduction	TMEC Amphitheater
9:15 am	Participant-Faculty Discussion	
9:30 am	Narrative Ethics: What Matters?	
10:15 am	Participant-Faculty Discussion	
10:30 am	Refreshment Break	
10:45 am	Medical Aid in Dying	
11:30 am	Participant-Faculty Discussion	
11:45 am	What Role Should the Public Play in the Setting of Science Policy?	
12:30 pm	Participant-Faculty Discussion	
12:45 pm	Transition to Lunch Sessions	Pick up tote lunch in TMEC Atrium
1:00 pm	▼ Lunch Sessions	
	HMS Center for Bioethics: Educational Opportunities	TMEC 250
	Topic-Based Facilitated Discussions • Surgical ethics • Pediatric ethics • Nurses • Women's health • Ethics consultants and committee chairs • Religion/chaplains • Attorneys • Social justice • Research ethics • Social workers	Rooms listed at registration table
1:45 pm	Learning Skills of Conflict Management for Challenging Ethics Consultations	
3:00 pm	Refreshment Break	TMEC Atrium
3:15 pm	Learning Skills of Conflict Management, continued	
4:30 pm	Evaluation and Closing Remarks	
4:35 pm	ADJOURN	

*All sessions will be held in the TMEC Amphitheater unless otherwise noted.

Friday, June 8, 2018*

8:00 am Breakfast**8:30 am****Ethical Issues in Women's Health and Assisted Reproduction***Louise King, MD, JD*

A brief overview of issues that can, and do, arise in women's health care ranging from abortion to assisted reproduction. Thereafter, a closer inspection of cases in media with an emphasis on examination of the legal/social context of care and the tensions that arise in ethical decision-making among stakeholders.

Learning Objectives:

- Identify major ethical topics that arise in women's health
- Explore ethical topics in women's health as highlighted by recent media
- Differentiate different stakeholders in women's health and the ethical questions they most often face
- Describe the tensions that can arise in ethical decision-making among stakeholders in women's health issues

9:15 am Participant-Faculty Discussion**9:30 am****Narrative Ethics: What Matters?***Martha Montello, PhD*

This session identifies the ways narrative methods work in clinical ethics consultation. A literary scholar and clinical ethicist examines two ethics cases where a narrative approach guided the conversations and helped shape an understanding of a good resolution.

Learning Objectives:

- Identify the narrative methods that can guide clinical ethics consultation
- Develop strategies for helpful conversations with patients and families making difficult decisions
- Explore what we mean by a good outcome or successful resolution of an ethics case

10:15 am Participant-Faculty Discussion

*All sessions will be held in the TMEC Amphitheater unless otherwise noted.

10:30 am Refreshment Break

10:45 am

Medical Aid in Dying

Brendan Abel, JD

This session outlines the intersection between ethics, the law, and issues related to end-of-life care.

Learning Objectives:

- Identify relevant US Supreme Court decisions related to "right-to-die" and physician assisted suicide/medical aid in dying
- Discuss the construction of various state laws to legalize medical aid in dying, and the different avenues that states have taken to pursue these laws
- Explore various ethical issues raised in current medical aid-in-dying laws

11:30 am Participant-Faculty Discussion

11:45 am

What Role Should the Public Play in the Setting of Science Policy?

Mildred Solomon, EdD

No matter the specific topic, nearly every publication of national bioethics commissions and many reports of the National Academy of Sciences, Engineering and Medicine end with a call for public engagement. Such calls have been particularly important in the era of CrisprCas9, given its potential uses for genome modification both in humans and in plants and nonhuman animals, such as disease-carrying mosquitos. But what is the normative rationale for public engagement? And if public engagement is valuable, what precisely do we mean, given that there is no one public, but many publics? Who should count as a stakeholder, and what should happen when large numbers of the public deny scientific evidence or prioritize questionable goals?

Learning Objectives:

- Be able to articulate reasons why bioethics should engage the public in the making of science policy;
- Be able to explain why it is difficult to engage the public in meaningful ways
- Become inspired to develop remedies for more meaningful public engagement in bioethical dilemmas bearing on science policy

Friday, June 8, 2018*

12:30 pm Participant-Faculty Discussion

12:45 pm Transition to lunch (Pick up bag lunches in TMEC atrium)

Lunch sessions

HMS Educational Opportunities

- Master of Bioethics
- Fellowship in Bioethics

Facilitated Discussions (Choose 1)

(Rooms and topics will be listed at the registration table)

- Surgical ethics
- Pediatric ethics
- Nurses
- Women's health
- Ethics consultants and committee chairs
- Religion/chaplains
- Attorneys
- Social justice
- Research ethics
- Social workers

1:45 pm

Learning Skills of Conflict Management for Challenging Ethics Consultations

Autumn Fiester, PhD

Given the emotionally charged nature of bedside ethical conflicts, interactions among the stakeholders in ethics disputes can sometimes turn hostile or acrimonious, making it impossible to have constructive dialogue. Conventional clinical ethics training often fails to teach clinical ethicists how to de-escalate conflicts that have become heated and intense. In this workshop, we will learn the subset of mediation skills that focus on conflict de-escalation, the techniques that can be employed to avoid conflict-acerbation, and the methods that can be used to prevent conflict escalation in the first place. The topics covered include diagnosis of the emotional sources of a stakeholder's anger, constructive responses to anger or frustration, dealing with one's own conflict-aversion, and techniques to calm explosive outbursts and transform them into productive dialogue.

Learning Objectives:

- Discover a framework for analyzing the content of stakeholder claims that can prevent conflict escalation
- Identify the moral emotions and explain their significance in managing difficult interactions
- Learn core de-escalation techniques to calm acrimonious ethics consultations

*All sessions will be held in the TMEC Amphitheater unless otherwise noted.

3:00 pm Refreshment Break

3:15 pm Learning Skills of Conflict Management for
Challenging Ethics Consultations *(continued)*

4:30 pm Evaluation and Closing Remarks

4:35 pm Adjourn

COURSE FACULTY 2018



BRENDAN ABEL, JD, is legislative and regulatory affairs counsel at the Massachusetts Medical Society, where he directs the state legislative affairs for the organization representing over 25,000 physicians in the Commonwealth. Prior to the Medical Society, he worked at Partners Healthcare, where he focused on legal and ethical issues in biomedical research, and was the health policy researcher at the *New England Journal of Medicine*. Upon completing undergraduate studies at Syracuse University, he earned his JD from Suffolk University Law School. He completed a fellowship in medical ethics at Harvard Medical School, where he has recently joined the Center for Bioethics to teach a course on health law, policy, and ethics. Brendan has been published in a number of academic publications including the *New England Journal of Medicine* and *The Hastings Center Report*. Brendan regularly presents on topics at the intersection of law and medicine.

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LACEY BRENNAN, MD, MBE, received a BMSc in pathology and toxicology from Western University, and an MD from the University of Calgary. She is interested in reproductive ethics and plans to pursue residency training in obstetrics and gynecology. Lacey received the Joseph Albert Award from the University of Calgary for elective study at Centers for Excellence. She is a recent graduate of the Center for Bioethics' Master of Bioethics program.

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MICHAEL BALBONI, PhD, ThM, MDiv, is an instructor at Harvard Medical School and a palliative care researcher at Dana-Farber Cancer Institute. He holds a PhD in theology from Boston University and completed post-doctoral training at Harvard's School of Public Health and Divinity School. He received a career development award as a faculty scholar with the Program on Religion and Medicine at the University of Chicago. His focus has included the development of a theology of medicine and a concentration in the theological underpinnings related to spiritual care in a pluralistic, secular medical context. In addition, he works as a social-scientific researcher with current empirical projects on spirituality and religion and their associations with end-of-life medical utilization and patient outcomes. He is coauthoring a book entitled *Hostility to Hospitality*, to be published 2018, which will explore the manifestations of spirituality and religion within the socialization processes and institutional structures experienced by medical professionals. He coedited *Spirituality and Religion Within the Culture of Medicine: From Evidence to Practice*.

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J. WESLEY BOYD, MD, PhD, is on faculty at the Center for Bioethics and is an HMS associate professor of psychiatry at Cambridge Health Alliance (CHA). He is the cofounder and codirector of the Human Rights and Asylum Clinic at CHA and is a psychiatrist for one of the principle training and teaching teams that work closely with psychiatry residents and medical students. Boyd graduated

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with a BA cum laude from Yale in philosophy. He received an MA in philosophy, a PhD in religion and culture, and a medical degree from the University of North Carolina at Chapel Hill. He completed a residency in psychiatry at Cambridge Hospital/Harvard Medical School and also completed a fellowship in medical ethics at Harvard Medical School. He has taught medical ethics and the humanities in various venues, and currently teaches “Medical Ethics and Professionalism” to first year Harvard Medical School students and the Harvard College seminar “Psychology of Religion.” He writes on issues of health care justice, humanistic aspects of medicine, and substance use.

REBECCA WEINTRAUB BRENDEL, JD, MD, is director of the master’s degree program at the Harvard Medical School Center for Bioethics, and is an assistant professor of psychiatry at Massachusetts General Hospital, where she directs law and ethics at the Center for Law, Brain, and Behavior. At Mass General, she provides medical oversight for the hospital’s inpatient guardianship team, and practices clinical and forensic psychiatry. Brendel has served in multiple leadership roles at Mass General. She graduated from University of Chicago Law School and Pritzker School of Medicine, and completed her psychiatry residency at Mass General and McLean Hospital, as well as a forensic psychiatry fellowship at Mass General. She is admitted to the Massachusetts Bar. Brendel is a fellow and president-elect of the Academy of Psychosomatic Medicine, and has served on the ethics committees of the Massachusetts Medical and Psychiatric Societies, and the American Academy of Psychiatry and the Law. Brendel’s clinical practice has focused on patients with complex psychosocial problems, including trauma, dementia, mental illness, homelessness, substance abuse, decisional incapacity, lack of community support, and poverty. This broad work has informed her educational efforts and research interests focusing on issues at the interface of psychiatry, medicine, law, ethics, and human rights.

STEPHEN D. BROWN, MD, is director of the Institute for Professionalism and Ethical Practice at Boston Children’s Hospital, which specializes in communication training for clinicians within a broad array of clinical domains. A pediatric radiologist with experience in obstetrical imaging, his scholarship explores the interface of ethics and communication around advanced diagnostic and therapeutic technology. His projects have included a national survey of prenatal care providers’ attitudes toward pregnancy management, a video series examining how values and communication interact in prenatal counseling, communication skills training for radiologists, and educational programming for disclosure and apology, brain death, and informed consent. He is a member of the Boston Children’s Hospital Ethics Advisory Committee, associate ethicist in the Hospital’s Office of Ethics, and faculty member in the HMS Center for Bioethics.

LYNN WEIN BUSH, PhD, MS, MA, is on the faculty of Pediatric Clinical Genetics a faculty member in the Program in Women and Children's Bioethics at Columbia University Medical Center, a member of the ethics committee at Morgan Stanley Children's Hospital. In addition, she serves as an ethicist and liaison on pediatric and genomic advisory committees for other academic medical centers and numerous professional organizations. Recent publications include policy statements in Genetics in Medicine. She creates bioethics plays and developed narrative genomics with Karen Rothenberg as a pedagogical approach to bring to life these complex issues and foster interdisciplinary discourse. Their book, *The Drama of DNA: Narrative Genomics*, provides an ethical analysis of adaptations from six of their original plays, all frequently staged at academic medical institutions and professional conferences with distinguished bioethicists and geneticists as actors.

ALEX CIST, MD, completed fellowships in pulmonary and critical care medicine and in clinical ethics at Harvard Medical School, and has combined these interests in her clinical work at Mass General since 1992. She is an active member of several ethics committees and performs clinical ethics services at Mass General, and trains new members of ethics committees at Mass General and other Partners hospitals. Her focus is in clinical ethics—especially in end-of-life care and in intensive care units. She advocates for holding multidisciplinary ethics rounds as a means of “keeping moral spaces open.” Her interest in manifestations of religion and spirituality among patients, families, and staff informs her bio-psycho-social-spiritual support approach to ethics consultation and conflict resolution. She is a consultant to the Mass General emergency preparedness group and to the Disaster Relief Ethics and Management team (DREAM team). She teaches in the ethics curriculum at HMS and serves on the Mass General Ethics in Clinical Practice Committee, the Partners Ethics Leaders Group, the Harvard Ethics Leaders Group, and the Harvard Task Force on Ethical Issues in Emergency Preparedness.

THOMAS COCHRANE, MD, MBA, received his combined degrees from the Tufts University School of Medicine and completed his residency in neurology in the Partners Neurology Program at Massachusetts General Hospital and Brigham and Women's Hospital(BWH). He then completed a fellowship in neuromuscular medicine and electromyography at BWH. He completed a fellowship in medical ethics at Harvard Medical School, and then served as a faculty fellow at the Safra Foundation Center for Ethics at Harvard University. From 2005-2017, he was as an attending neurologist specializing in neuromuscular disease at BWH. He also worked as the senior ethics consultant at BWH and served on the Partners IRB. He taught medical ethics to HMS students, residents, faculty, and nursing staff at all levels, and was the first director of neuroethics at the HMS Center for Bioethics. In

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2018, he joined Biogen as a medical director, and is responsible for medical oversight of natalizumab (Tysabri), a drug for multiple sclerosis, in the U.S.

RODNEY P. DISMUKES, PHD, MHA, MS, is the clinical associate director of Mental Health Services for the VA Boston Healthcare System and is an HMS instructor in psychiatry. He chairs the VA Boston's Ethics Consultation Committee. He earned his PhD in clinical psychology from Auburn University and a master of health care administration degree from the University of North Carolina, Chapel Hill. He completed an MS in biomedical ethics from the Alden March Bioethics Institute at Albany Medical College. He has worked as a mental health clinician and clinical administrator in a wide variety of treatment settings in both the public and private sectors. His areas of interest include the ethical delivery of mental health services and understanding how healthcare practitioners best acquire skills in professionalism and ethical decision-making. He is interested in improving processes and systems supporting the areas of clinical and organizational ethics in health care settings.

AUTUMN FIESTER, PhD, is assistant chair for education and training in the Division of Medical Ethics at the Perelman School of Medicine at the University of Pennsylvania. She is the director of the Penn Program in Clinical Conflict Management, which promotes conflict resolution training for formal clinical ethics consultations and ethics conflicts at the bedside. Fiester is a consultant for the Hospital of the University of Pennsylvania Ethics Service, and she conducts workshops in conflict management around the country. She has been a member of the American Society for Bioethics and Humanities task force on clinical ethics consultation professionalization (Clinical Ethics Consultation Affairs Standing Committee). She is also a member of the Advisory Board of the Singapore CEN-TRES Project (Clinical Ethics Network, Training, Research and Support Initiative) aimed at developing the capacity of clinical ethics committees in Singapore. She is a member of GABEX: Global Alliance of Biomedical Ethics Centers sponsored by the University of Tokyo, designed to create a collaborative, international network of bioethics centers of excellence. She was also a contributing author of the EU-sponsored CHIMBRIDS project (Chimeras and Hybrids in Comparative European and International Research), which produced recommendations to the EU federation about the ethical issues surrounding chimera and hybrid research.

CHARLENE GALARNEAU, PhD, is associate professor of women's and gender studies, and director of the Health and Society program at Wellesley College. She is a member of the faculty of the HMS Center for Bioethics, where

she teaches a course on race, gender and bioethics in the master's program. Her recent book, *Communities of Health Care Justice*, argues that just health care must engage communities as critical moral participants in discerning the nature of justice in health care. She completed a fellowship in medical ethics at HMS, was member of the ethics committee of the Tufts-New England Medical Center, and consultant to the development of a municipal ethics committee in Portland, Maine. Her articles appear in the *American Journal of Bioethics*, *Health and Human Rights*, *The Hastings Center Report*, *Public Health Ethics*, *Journal of Bioethical Inquiry*, and *Journal of Health Care for the Poor and Underserved*. She received a doctorate in religion from Harvard University with a concentration in religious social ethics and health policy, and a master's degree from the Iliff School of Theology.

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CHARLOTTE HARRISON, PhD, JD, MPH, is hospital ethicist and director of the Office of Ethics at Boston Children's Hospital (BCH), where she also cochairs the Ethics Advisory Committee. She has served as director of the BCH literature and medicine program and has cochaired organizational ethics task forces addressed to issues in the provision of extracorporeal life support and the conduct of organ donation after circulatory death. At the HMS Center for Bioethics, she cochairs the organizational ethics consortium with James Sabin, MD. Before entering the field of bioethics, Charlotte graduated from Harvard Law School and practiced law for fifteen years, both at private firms and in the Office of Technology Affairs at Massachusetts General Hospital. She then returned to Harvard for masters-level training in ethics and public health. She completed her PhD with a dissertation addressed to the ethics of professional collaboration in conditions of uncertainty. She has been a fellow in medical ethics at Harvard Medical School and has served on the Institutional Review Board of the Dana-Farber Cancer Institute. Her bioethics-related writing has been published in the *American Journal of Law and Medicine*, *JAMA Pediatrics*, *Lancet Respiratory Medicine*, *Pediatric Critical Care Medicine*, and *Transplantation Proceedings*.

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SPENCER P. HEY, PHD, works on ethical, policy, and methodological issues at the intersection of philosophy of science and biomedical research ethics. He has published on a variety of topics, including the ethics of placebo-controlled trials, adaptive randomization, risk minimization in early-phase human trials, discordant evidence, complexity and coordination problems in cancer biomarker research, and why clinical investigators ought to make explicit likelihood predictions in their research protocols. He has also developed a graph-theoretic approach to representing medical research programs. Published examples of the approach thus far have included research programs in tuberculosis and diagnostic development in precision medicine, but more examples—particularly in cancer drug development—will

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be appearing in print soon. Hey received his PhD in philosophy from the University of Western Ontario and a BA in philosophy from the University of Illinois, Chicago. He is currently a faculty member at the HMS Center for Bioethics and a research fellow in the Department of Medicine and the Division of Pharmacoepidemiology & Pharmacoeconomics at the Brigham and Women's Hospital. He previously held a research fellowship in the Biomedical Ethics Unit at McGill University and a visiting scholarship at the University of Oxford.

EDWARD M. HUNDERT, MD, is the Dean for Medical Education and the Daniel D. Federman, MD Professor in Residence of Global Health and Social Medicine and Medical Education at Harvard Medical School. Hundert also serves as associate director of the Center for Bioethics at HMS. Over the past 25 years, he has served as president of Case Western Reserve University, dean of the University of Rochester School of Medicine and Dentistry, and associate dean for Student Affairs at Harvard Medical School. An internationally known scholar, educator, psychiatrist, and ethicist, he has held professorial appointments in psychiatry, medical ethics, cognitive science, and medical humanities. His most recent duties at Harvard before serving as dean for medical education included directing the Academy Fellowship in Medical Education for HMS faculty and the medical ethics and professionalism curriculum for HMS students. Hundert earned his bachelor's degree in mathematics and the history of science and medicine from Yale University. He attended Oxford University as a Marshall Scholar, and later earned an MD from Harvard Medical School. He completed his psychiatric residency at McLean Hospital. He has received numerous teaching, mentoring, and diversity awards. He is a member of the board of TIAA. He has previously served on the boards of the Association of American Universities, the Association of American Medical Colleges, the Liaison Committee on Medical Education, and the Rock and Roll Hall of Fame. He cochaired the Institute of Medicine's National Summit on Health Professions Education. Hundert has written dozens of articles and chapters on a variety of topics in psychiatry, philosophy, medical ethics, and medical education, as well as two books: *Philosophy, Psychiatry and Neuroscience: Three Approaches to the Mind* and *Lessons from an Optical Illusion: On Nature and Nurture, Knowledge and Values*.

MARTHA JURCHAK, RN, PhD, is the executive director of the Ethics Service in the Office of Clinical Ethics at Brigham and Women's Hospital. She cochairs the ethics committee at Brigham and Women's and manages the 24/7 ethics consultation service, which is open to patients, families, and staff at the hospital. Working in clinical ethics since 1985, she has written and published on the topic in *The Journal of Clinical Ethics*, *American Journal of Bioethics*, and *The Hastings Center Report*. She speaks at national and international conferences, and is faculty in the HMS Center for Bioethics where she currently teaches a seminar in the master's program on ethics consultation.

EMILY NAGISA KEEHN, JD, is associate director of the academic program in the Human Rights Program (HRP) at Harvard Law School. Her work primarily focuses on the intersection of human rights issues with criminal justice, gender, and health. Prior to joining HRP, Keehn was the head of policy development and advocacy at Sonke Gender Justice in Cape Town, where she directed strategic litigation, parliamentary engagement, research, and advocacy related to HIV and AIDS, gender equality, sexual and gender-based violence, policing, and penal reform. Keehn has published research in the journal *Feminist Criminology*, presented before the South African Parliament, and has helped shape national policies on corrections, gender, and health. Previously, Keehn worked for the Health & Human Rights Law Project at UCLA School of Law. She has a BA in anthropology from UC San Diego, a JD from UCLA School of Law, and is a member of the State Bar of California.

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LOUISE P. KING, MD, JD, is an assistant professor of obstetrics, gynecology and reproductive biology at Harvard Medical School and a surgeon within the Division of Minimally Invasive Gynecologic Surgery at Beth Israel Deaconess Medical Center. As director of reproductive ethics at the HMS Center for Bioethics, King teaches a course on reproductive ethics and women’s health. She completed her JD at Tulane Law School before attending medical school at University of Texas Southwestern Medical Center. She completed her residency in obstetrics and gynecology at Parkland Hospital in Dallas, Texas and her fellowship in minimally invasive surgery at Stanford University. Her areas of interest in medical ethics focus on questions of informed decision making and assisted reproduction.

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KAARKUZHALI (BABU) KRISHNAMURTHY, MD, MBE earned her MD at the University of Maryland School of Medicine, and her MBE at Harvard Medical School. After her residency in the Harvard-Longwood Area Neurology Program, and fellowship in epilepsy and clinical neurophysiology at Beth Israel Deaconess Medical Center and Boston Children’s Hospital, she joined the faculty at Beth Israel Deaconess Medical Center to develop and run the Women’s Health in Epilepsy program, where she counselled and followed over 400 women with epilepsy through one or more pregnancies. Her ethics contributions included roles as a vice-chair of the Institutional Review Board, director of the Human Subjects Protection Office, and co-chair of the Ethics Advisory Committee. She works at Steward Medical Group, setting up a system-wide clinical epilepsy program, and EEG monitoring service. She also has a system-wide appointment as an ethics associate where she will be helping to develop and support educational programs and resources for ethics committees at the member hospitals. In June, she will become chair of the Ethics Committee at St. Elizabeth’s Medical Center.

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MICHAEL IEONG, MD, is an assistant professor in the Department of Medicine. He attends in the Medical Intensive Care Unit and on the Pulmonary Consult service of Boston Medical Center. He sees patients in the Pulmonary and Allergy Outpatient Clinic and oversees the cardiopulmonary exercise testing program. Ieong's focus is on translational medicine. His research focuses on the innate immunity of the lung in response to infection, particularly in the context of immune compromise such as HIV-infection. His clinical expertise is in critical care medicine and the administration of intensive care units. He is an experienced research bronchoscopist and collaborates with a number of investigators to provide primary lung cells and lavage for study. He is a member of the Pulmonary Immunology Group and the Center for HIV/AIDS Care and Research. He is cochair of the Ethics Advisory Committee at Boston Medical Center.

JOHN MAYER, MD, received his MD from Yale Medical School and trained in general and cardiothoracic surgery at the University of Minnesota. He is a professor of surgery at Harvard Medical School and the first Tommy Kaplan Chair in Cardiovascular Studies at Boston Children's Hospital. He is interested in health policy and has served as a Society of Thoracic Surgeons (STS) representative to the AMA Relative Value Update Committee and the STS Health Policy Workforce. He is the past president of the STS, past chair of the STS Finance Committee, and continues to serve on the STS Health Policy Council and on the STS Standards and Ethics Committee.

JONATHAN MARRON, MD, MPH, is an instructor in pediatrics at Harvard Medical School and a junior faculty member in pediatric hematology/oncology at Dana-Farber Cancer Institute and Boston Children's Hospital. He received his MD at the David Geffen School of Medicine at UCLA, and his MPH from the Harvard T.H. Chan School of Public Health. He served on ethics committees at Stanford University Hospital and the University of Chicago, Pritzker School of Medicine. Jonathan has taken an active role with the Boston Children's Hospital Ethics Advisory Committee and Office of Ethics.

WENDY MCHUGH, RN, MS, is associate director of Ethics Programs at Beth Israel Deaconess Medical Center in Boston. In this role she provides ethics consultations, facilitates monthly ethics rounds, and co-coordinates a monthly ethics case conference. She is the director of the Ethics Liaison Group and a member of the Ethics Advisory Committee. McHugh is also a member of the Harvard Ethics Leadership Group.

MARTIN MCKNEALLY, MD, PHD, is professor emeritus of surgery at the University of Toronto, the Joint Centre for Bioethics, and Toronto General Hospital in the University Health Network. He completed general and cardiothoracic surgical training at the University of Minnesota. He served as professor of surgery and chief of the Division of Cardiothoracic Surgery at the Albany Medical Center in Albany, New York until 1990. From 1990 to 1995, he served as chairman of the Division of Thoracic Surgery at the University of Toronto. Since then, he has been a member of the University of Toronto Joint Centre for Bioethics, learning, teaching and conducting research on ethical issues in surgery, with a primary focus on informed decision making and innovative treatment. He has served as director of the American Board of Thoracic Surgery, secretary of the American Association for Thoracic Surgery, president of the Thoracic Surgery Directors Association, and president of the Thoracic Surgery Foundation for Research and Education. He is a member of the Society of Thoracic Surgeons' Standards and Ethics Committee, and ethics editor of the *Journal of Thoracic & Cardiovascular Surgery*.

AIMEE MILLIKEN, PHD, is the Wiese Postdoctoral Fellow in Clinical Bioethics at Brigham and Women's hospital in Boston. She has practiced as a critical care nurse for nearly ten years, and she received her PhD from Boston College. Her dissertation involved the development and psychometric evaluation of the Ethical Awareness Scale, an instrument to measure ethical awareness in critical care nurses.

CHRISTINE MITCHELL, RN, MS, MTS, is executive director of the HMS Center for Bioethics. She received her bachelor's and master's degrees in science from Boston University School of Nursing and a master's degree from Harvard where she majored in philosophical and religious ethics as a Kennedy Fellow in Medical Ethics through the Interfaculty Program at Harvard Medical School (HMS), Harvard Divinity School, and Harvard School of Public Health. She is an elected Fellow of the American Academy of Nurses. Mitchell founded the ethics program at Boston Children's Hospital, directing the ethics consultation service and leading the Ethics Advisory Committee for 30 years. She served as associate director of clinical ethics at HMS's Division of Medical Ethics where she developed the Ethics Leadership Group, the Harvard Clinical Bioethics Course, and an all-volunteer citizen Community Ethics Committee for informed public input on ethical aspects of health care and health policies. She leads the monthly Harvard Clinical Ethics Consortium discussion of ethics cases and teaches in the HMS Medical Ethics Fellowship program. Her research has focused on ethics consultation, and public engagement in policies regarding resource allocation related to major natural disasters or pandemics. Mitchell has served on numerous national committees and commissions, most recently, the Ethical Legal and Social Aspects Committee for the Human Brain Project. She lectures nationally and internationally on issues in clinical

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ethics. She edits a regular series of ethics cases for *The Journal of Clinical Ethics* and has written on numerous topics in bioethics for the *American Journal of Nursing*, the *New England Journal of Medicine*, and several specialty clinical journals, as well as in the popular press.

MARTHA MONTELLO, PhD, is lecturer in the Harvard Medical School Center for Bioethics. Montello is editor-in-chief of *Perspectives in Biology and Medicine*. In Boston, she teaches narrative methods in clinical ethics with master's students and fellows at the HMS Center for Bioethics. She mentors Harvard medical students and physicians on narrative methods, medical humanities, and literature and medicine, and teaches in the Brigham and Women's Hospital Residency Program in Primary Care and Population Medicine. In Kansas City, she is director of the Medical Writing Center at Children's Mercy Hospital. She holds a visiting professorship in narrative ethics at the University of Pavia, Italy. Montello lectures nationally and internationally on literature and medicine and narrative approaches to bioethics. Her scholarship has been published widely including in *The Chronicle of Higher Education*, *The Hastings Center Report*, *New England Journal of Medicine*, *Journal of Clinical Ethics*, *Annals of Internal Medicine*, *Academic Medicine*, *New Orleans Review*, and in "Boston Studies in the Philosophy and History of Science." She is coeditor of *Stories Matter: The Role of Narrative in Medical Ethics*.

CAROL L. POWERS, JD, is cofounder and chair of the Community Ethics Committee (CEC). The CEC was a result of Carol's bioethics fellowship at Harvard Medical School. Operating under the auspices of the Harvard Ethics Leadership Group for the HMS Center for Bioethics, the CEC is part of the nonprofit Community Voices in Medical Ethics, Inc., and was developed to serve as a community-based policy-review resource to the teaching hospitals, as well as an educational resource to the varied communities from which the members come. The CEC is a group of citizens from the Greater Boston area who meet regularly to provide public input on ethical aspects of health care. They have published many white papers, which are accessible on their blog: www.medicalethicsandme.org. Carol has coauthored articles published in the *American Journal of Bioethics*, *Surgery*, and *Dignitas*. She served for over twenty years as a community member of the Boston Children's Hospital Ethics Advisory Committee. In her spare time, she maintains a legal practice focusing on estate planning and representation of the Newburyport Redevelopment Authority.

ELIZABETH REIS, PhD, is a professor at the Macaulay Honors College at the City University of New York where she teaches courses on transgender issues, reproductive technologies, the politics of women's health, and medical ethics. Before that

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moral philosophy, philosophical and theological bioethics, end-of-life medical ethics, and hospice palliative care. He is a principal faculty member for the Initiative on Health, Religion, and Spirituality, an interfaculty initiative across Harvard University which aims to be a research catalyst for an integrated model of spirituality, public health, and patient care in dialogue with spiritual communities. In addition to his work at Harvard, Patrick is associate professor of philosophical theology and ethics at Gordon-Conwell Theological Seminary. He previously worked as the ethics coordinator for Angela Hospice Care Center in Livonia, MI. He has served on the Ethics Advisory Council for the National Hospice and Palliative Care Organization, the board for the Michigan Hospice Palliative Care Association, the Community Ethics Committee sponsored by the Harvard Ethics Leadership Group, and on Boston Children's Hospital Ethics Advisory Committee. Patrick has taught courses and given talks to medical professionals, educators and community leaders, and clergy across the globe.

ROBERT TRUOG, MD, MA, is the Frances Glessner Lee Professor of Medical Ethics, Anaesthesiology & Pediatrics and director of the Center for Bioethics at Harvard Medical School. Truog received his medical degree from the University of California, Los Angeles and is board certified in the practices of pediatrics, anesthesiology, and pediatric critical care medicine. He also holds a master's degree in philosophy from Brown University and an honorary master of arts from Harvard University. He practices pediatric intensive care medicine at Boston Children's Hospital, where he has served for more than 30 years, including a decade as chief of the Division of Critical Care Medicine. As chair of Harvard University's Embryonic Stem Cell Research Oversight Committee, he is engaged in the challenges of defining the ethical parameters of stem cell research and regenerative biology. Truog has published more than 300 articles in bioethics and related disciplines, and he authored current national guidelines for providing end-of-life care in the intensive care unit. His books include *Talking with Patients and Families about Medical Error: A Guide for Education and Practice*, and *Death, Dying, and Organ Transplantation*. He lectures nationally and internationally, and is an active member of numerous committees and advisory boards.

MILDRED Z. SOLOMON, EdD, is professor of anaesthesia (part-time) at Harvard Medical School and a core faculty member of the School's Center for Bioethics, where she directs the Center's fellowship in bioethics. Professor Solomon is the president of The Hastings Center, an independent research institute that explores ethical issues in health, health care, and the life sciences. A bioethicist and social science researcher who conducts both normative and empirical ethics research, Solomon's own scholarship has focused on the ethics of end-of-life care for both adults and children, organ transplantation, research ethics, particularly related

to oversight of comparative effectiveness and implementation science, as well as professionalism and responsible conduct of research. She has served on committees of the National Academies of Science, on the U.S. Secretary of Health and Human Services' Advisory Committee on Organ Transplantation, and has consulted to numerous foundations and government agencies. Before assuming the leadership of The Hastings Center, Solomon was senior director of implementation science at the Association of American Medical Colleges. Solomon earned her doctorate in educational research methods and adult learning at Harvard University and her BA from Smith College.

DAVID SONTAG, JD, MBE, is first deputy general counsel at Beth Israel Deaconess Medical Center (BIDMC) and a lecturer on medicine at Harvard Medical School. His current legal practice focuses on advising and resolving legal and compliance issues related to corporate and clinical affiliations and other business relationships with BIDMC, including its relationship with its accountable care organization. David also advises medical center clinicians regarding guardianships, health care proxies and related informed consent issues, and oversees the process for obtaining guardianships for medical center patients. David serves as co-chair of the BIDMC Ethics Advisory Committee and is involved in BIDMC's Ethics Liaison program, and is often consulted and asked to speak about legal and ethical issues that arise in the clinical setting. In conjunction with his law practice, David has taught various courses related to health law and bioethics at Drexel University, Rutgers School of Law, Camden, and the University of Pennsylvania Center for Bioethics. He currently teaches the capstone seminar for the master of bioethics program at Harvard Medical School. David is an active member of the Boston Bar Association and previously served as cochair of the health law section. Before joining BIDMC, David served as a federal judicial clerk, and was in private practice, where he represented health care providers, medical device and pharmaceutical companies, and private equity investors in health care-related companies. David is a cum laude graduate of Washington University in St. Louis, and a graduate of the University of Pennsylvania Law School. He holds a master of bioethics from the University of Pennsylvania Medical School.

M. SHELEAGH SOMERS, MSW, LICSW, is a clinical social worker at Beth Israel Deaconess Medical Center, a graduate of Simmons School of Social Work, and a two-year post graduate program in psychodynamic psychotherapy theory and practice. She works with OB/GYN patients and with parents who have an infant admitted to the NICU. She is a member of the hospital-wide Ethics Support Service, facilitates NICU Ethics Rounds and serves on a number of NICU related committees. She is also actively involved with Boston Children's Hospital Institute for Professionalism and Ethical Practice and the Program to Enhance

Relational and Communication Skills. Additionally, Sheleagh has an active psychotherapy private practice. She looks forward to broadening her perspective and deepening her understanding in the application of ethical principals in the clinical setting. Her interests include addressing ethical issues associated with the moral distress experienced by providers at the bedside, and end-of-life decision making. She hopes to focus on the intersection of medical ethics, enhanced communication, and the relational model of clinical practice.

LAURA SPECKER SULLIVAN, PhD, received a PhD in philosophy and a graduate certificate in Japanese Studies from the University of Hawaii at Manoa. Her dissertation focused on cross-cultural bioethics and informed consent in Japan, and her research was funded by the Crown Prince Akihito Scholarship Foundation. From 2015 to 2017 she was a joint postdoctoral fellow at the Center for Sensorimotor Neural Engineering at the University of Washington, Seattle, and at the National Core for Neuroethics, University of British Columbia. At the Harvard Medical School Center for Bioethics Laura has continued to conduct post-doctoral research on ethics, neuroscience, and culture, and cotaught a neuroethics course in the master of bioethics program.

LAUREN TAYLOR, MPH, MDiv, is a doctoral candidate in the management track of the health policy program at Harvard University. In 2013, Lauren and Elizabeth Bradley, jointly authored *The American Health Care Paradox*, which argued for additional attention and funding for social services in order to improve health. She graduated as a Presidential Scholar from Harvard Divinity School, where she served as the research and development director in the Science, Religion and Culture program. Lauren received a BA in the history of science/history of medicine, and a master in public health from Yale University. She has been a fellow at the Harvard Petrie-Flom Center and Harvard Global Health Institute. Taylor has also published peer-reviewed articles on grand strategy in global health, scale-up of public health innovations, and the empirical relationship between health and social service spending in the United States.

DAVID URION, MD is director of education and residency training programs in child neurology and neurodevelopmental disabilities at Boston Children's Hospital (BCH), where he holds the Chares F. Barlow Chair in Neurology along with serving as the director of Behavioral Neurology Clinics and Programs at BCH. He received his undergraduate degree at Dartmouth College, his medical degree at Stanford University School of Medicine, and after training in internal medicine and in pediatrics at BCH, he trained in child neurology in the Harvard Longwood Neurology Training Program. He has served on the Ethics Advisory Committee at

BCH, and the ethics committee of the Child Neurology Society. He is active in national neurology education programs, serving as the chair of the graduate education committee of the Professors of Child Neurology, and serves on the graduate education subcommittee of the American Academy of Neurology (AAN), the residency in-training examination advisory committee of the AAN, and the advisory committee to the Accreditation Council for Graduate Medical Education (ACGME) for the Child Neurology Milestones Project. He was the chair of the advisory committee to the ACGME for the Neurodevelopmental Disabilities Milestones Project, and is the president-elect of the Professors of Child Neurology. He is the author of *Compassion as a Subversive Activity*, and editor of the forthcoming *Principles and Practice of Pediatric Behavioral Neurology*.

LYNNE BRADY WAGNER, MA, CCC-SLP, is a speech-language pathologist, the director of the Stroke Program, and chair of the Ethics Advisory Committee at Spaulding Rehabilitation Hospital in Boston. She earned a graduate certificate in healthcare ethics from Rush University Medical School and was a disability ethics fellow at Rehabilitation Institute of Chicago and the MacLean Center for Clinical Medical Ethics at the University of Chicago. Lynne is a former member of ASHA's Board of Ethics and serves on the group's steering committee as coordinator. She is an instructor and teaches health care ethics at the Massachusetts General Hospital Institute for Health Professions. Lynne has numerous publications in peer reviewed journals and has lectured nationally on the topic of ethics and disability.

RICHARD WHYTE, MD, MBA, is the vice chair of surgery at Beth Israel Deaconess Medical Center and a professor of surgery at Harvard Medical School. Richard received his BS in chemistry, his MD from the University of Pittsburgh, and MBA from the Wharton School at the University of Pennsylvania. He is interested in bioethical issues pertaining to the field of surgery, particularly cardiothoracic surgery. Richard is on the ethics committees of two national surgical organizations: the Society of Thoracic Surgeons (chair) and the American College of Surgeons.

CASE DISCUSSION GUIDES



Case Discussion Guide

Wednesday Luncheon Seminar Discussion

A Mother's Death*

Margaret was in her late 40s when she began to have periods of confusion and forgetfulness, which were eventually diagnosed as early severe progressive Alzheimer's disease. Her son was her health care proxy. When she was no longer able to live at home with her three children, Margaret was admitted to a locked residential psychiatric facility where multiple medications and treatments were tried with little apparent improvement or relief. Margaret was restless, inarticulate, emotionally labile, and had lost a lot of weight. Her children believed she was suffering, though not all the staff agreed. Opioids were prescribed but some nurses felt it was wrong to medicate Margaret when she did not seem to be in physical pain. An ethics consult was requested, and Margaret's children wrote a letter stating what they believed she would want and what they wanted for her. Later, Margaret was evaluated for admission to a hospice with the possibility of palliative sedation—sometimes called “terminal sedation” or “continuous deep sedation as comfort care until death.” Although palliative sedation was not needed, Margaret died peacefully ten days after she walked into the hospice facility.

1. What are the ethical issues in this case? How about specific ethical questions? Try starting a sentence with “Should...?” or “Is it ethically permissible to...?” or “Given (uncertainty or conflict), what decisions or actions are ethically justifiable?”
2. If this case were brought to your ethics committee, how would it be handled? (Or, how do you think an ethics committee should deal with such a case?)
3. How do you think such concepts as patient autonomy, parental autonomy, and professional autonomy might apply in this case?
4. What do you think about the ethics of palliative sedation? Is it justifiable? Why or why not? How would you distinguish between palliative sedation and euthanasia?
5. Identify alternative choices. What do you think are the possible benefits to seek and risks of harm to avoid?
6. What do you think about the moral reasoning in the children's letter to the ethics committee?
7. How do your values and beliefs about what constitutes a “good death” enter into ethical deliberations?

* Cases from the Harvard Ethics Consortium, *The Journal of Clinical Ethics*, 17:4 (2006), 331-368

Case Discussion Guide

Thursday Luncheon Seminar Discussion

Jamie's Story*

Jamie was flown to the hospital and admitted to the trauma service after experiencing a total degloving of his face and scalp, and fractured cervical vertebrae from getting his hair caught in a piece of rotary equipment at work. Plastic surgery on his face and scalp was innovative and ultimately successful, though his spine and neck were not stabilized during the early postoperative period in order to maximize blood flow and healing to his face. At first, it was not clear whether Jamie had survived with his cognition intact. He and his girlfriend, Shannon, had a rocky relationship, and he hadn't seen his foster father, Gary, for years; however, they had both come to the hospital to be with him. They said Jamie would not want to live if he were paralyzed (which he was). Once his nurse and others realized Jamie was "in there," the concern about who should make decisions for him changed. At times, Jamie felt discouraged and communicated to his nurse that he wanted to die. Another time, he and Shannon talked about getting married in the hospital. During his long hospitalization, many staff from other units came to see Jamie. Big and small questions about what the nurses, doctors, Jamie, Shannon, and others should do were discussed in the break room, on rounds in the surgical ICU, and at ethics committee meetings. Eventually, Jamie was transferred to a nursing home.

1. What difference, if any, does the care setting make in what ethical questions arise and how they are addressed? You might compare this to setting changes in yesterday's case—Margaret's story.
2. What do you see as ethical questions in this case?
3. Are these the sort of questions that should be handled with an ethics consult or by an ethics committee? Which questions? Why? Why not? In what other ways, and in what other places, do you think ethical questions in this case are asked and answered?
4. Do you see things any differently when you use a narrative "lens" or some other approach to analyzing the ethical aspects of Jamie's story?
5. Should innovative surgery like Jamie's involve oversight or review by the hospital's institutional review board or research review committee? Retrospectively?
6. What did you think about the choice between maximizing success for reimplantation of Jamie's face and scalp rather than preventing further spinal damage? How should differences of opinion between services (plastic surgery and neurosurgery) about what is most important to the patient be handled? Is that an ethical issue?
7. Some patients have gotten married in the hospital—even in the SICU where Jamie was. Should Pamela have helped to make that happen for Jamie and Shannon? What weight, if any, should her view have had about what was good for Jamie when it came to marrying Shannon?
8. How do you apply the principles of beneficence and autonomy when the patient's sense of self is so transformed by trauma? What if you think the patient might change his mind once he adapts to his "new self" the way Jamie seems to have?

*Cases from the Harvard Ethics Consortium, *The Journal of Clinical Ethics*, 13:2 (2002) 146-159.

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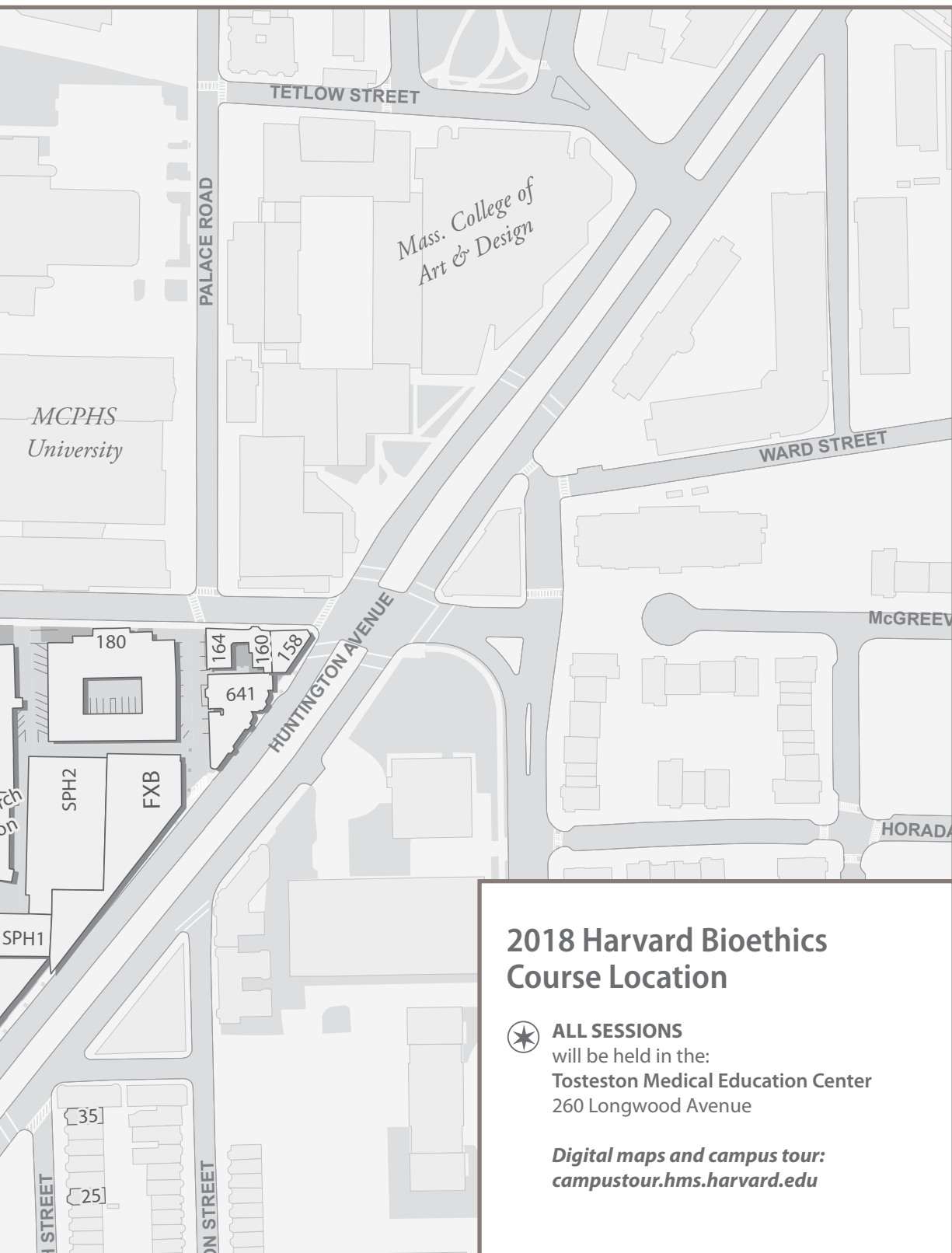
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