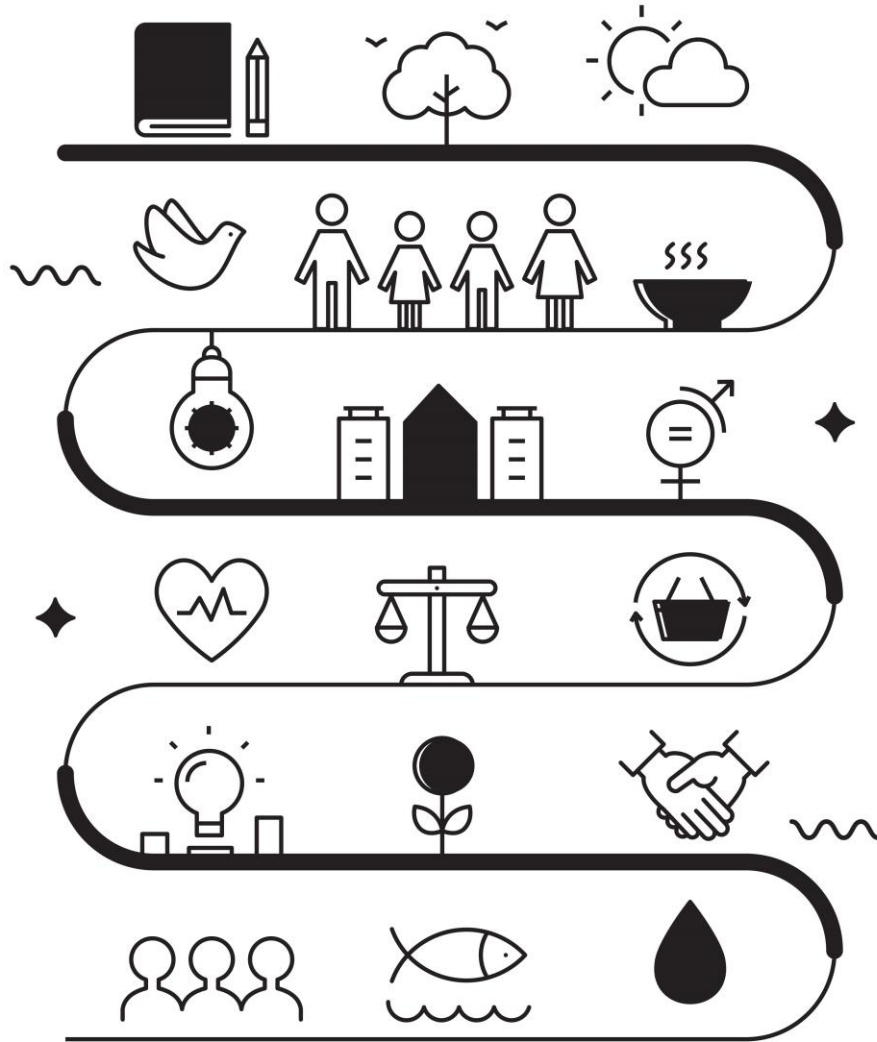


UW Medicine

DEPARTMENT OF
BIOETHICS & HUMANITIES

Health through Social Justice



ANNUAL REPORT

2018 – 2019

2018-2019 FACULTY HIGHLIGHTS



ERIKA BLACKSHER, PhD

ASSOCIATE PROFESSOR

- Published **Shrinking Poor White Life Spans: Class, Race, and Health Justice** as a target article for *The American Journal of Bioethics*, which attracted 10 commentaries.
- Invited to present at the **National Academies of Science's Committee on Rising Midlife Mortality Rates and Socioeconomic Disparities** (because of the above article).
- Presented "**Challenges to Talking About APOL1 Gene Variants and Racial Disparities in Kidney Disease**," as an invited distinguished faculty at the 2018 American Society of Nephrology Kidney Week: Racial Inequalities in Kidney Diseases: Connecting Social Factors to Genetic Risk.
- Invited research group member for The Hastings Center's "**How Should the Public Learn? Reconstructing Common Purpose and Civic Innovation for a Democracy in Crisis**," and invited to contribute to The Hastings Center Report "**Reckoning with Whiteness and Renewing Our Capacities for Civic Listening and Learning in a Polarized and Unhealthy America**."

DEB BOWEN, PhD

PROFESSOR



- Completed **randomized trial of website testing** and working on data analysis as part of the **NIH Electronic Medical Records and Genomics Network's eMERGE III** to assess health impact, cost effectiveness, and ethical, legal and social implications of reporting genetic variants on a broader population scale for patients, clinicians and healthcare institutions.
- Completed **participant recruitment** for MAGENTA, a **national randomized trial of genetic testing methods for women at risk of breast/ovarian cancer**. Currently conducting follow-up procedures and data analyses.
- Continued participant recruitment for our national **Dilated Cardiomyopathy Precision Medicine study** and beginning data collection for the survey of probands and family members.
- Completed analyses of Seattle Cancer Care Alliance data on **high risk testing among early adopters of genetic testing for BRCA**, with subsequent data analysis.

2018-2019 FACULTY HIGHLIGHTS



GINA CAMPELIA, PhD ASSISTANT PROFESSOR

- Published (with T. Tate) “**Empathetic Practice: The Struggle & Virtue of Empathizing with a Patient’s Suffering**” in the Hastings Center Report (March/April 2019).
- Presented “**Gendering Capacity: The Two Sided Vulnerability of Survivors of Abuse**” at Canadian Bioethics Society Annual Meeting and Academy for Professionalism in Healthcare Annual Meeting.
- Co-created (with Tracy Brazg) the **Bodemer Interprofessional Ethics Labs**, collaboratively sponsored by the Bodemer Endowed Lectureship and The UW Center for Health Sciences Interprofessional Education Research and Practice.
- Developed and taught the new **Advanced Training in Healthcare Ethics** online certificate course “**Healthcare Ethics Methods.**”

DENISE DUDZINSKI, PhD, MTS PROFESSOR & CHAIR



- Successfully launched the department's new online **Advanced Training in Healthcare Ethics** certificate program.
- Joined ethics committees for the **Society of Critical Care Medicine & American Society of Clinical Oncology.**
- Published (with A. Kon) “**Navigating End-of-Life Decisions Using Informed Nondissent**” in the American Journal of Bioethics.
- Plenary Speaker, “**Tackling Moral Distress with the Moral Distress Map**” at the National Nursing Ethics Conference.

2018-2019 FACULTY HIGHLIGHTS



MALIA FULLERTON, DPhil ASSOCIATE PROFESSOR

- **Co-authored 10 peer-reviewed publications** and one online commentary on a range of research ethics topics in clinical translational genomics, community engagement, and genealogical approaches to forensic genetic testing.
- Resubmitted an R01 application (with S. Lee) "**Empirical Engagement with "Embedded Ethics" (E4): Lessons from the Field**" to the National Human Genome Research Institute's Ethical, Legal, and Social Implications (ELSI) program. The proposed project will use a stakeholder engagement approach to examine the experience and perspectives of ELSI researchers and genome scientists involved with "embedded ELSI" approaches pursued in the context of genomic research.
- **Chaired the doctoral committee** of Sarah C. Nelson (Public Health Genetics), who successfully defended her dissertation "Third-party interpretation of personal genetic data: the tools, users, and implications for policymaking."
- Served as an invited member of the **Population Screening Working Group, Genomics and Population Health Action Collaborative, Roundtable on Genomics and Precision Health**, National Academies of Sciences, Engineering, and Medicine.

THOMAS GALLAGHER, MD PROFESSOR



- Received the **2018-John M. Eisenberg Patient Safety and Quality Award for Individual Achievement**, presented by the National Quality Forum and The Joint Commission.
- Published (with White AA, Sage W, Osinska PH, Salgaonkar MJ) "**Patient safety and the ageing physician: a qualitative study of key stakeholder attitudes and experiences**" in BMJ Quality & Safety.
- Published (with Fisher KA, Smith KM, Huang JC, Borton JC, Mazor KM) "**We want to know: patient comfort speaking up about breakdowns in care and patient experience**" in BMJ Quality & Safety.
- Published (with Mello MM, Sage W, Bell SK, McDonald TB, Thomas EJ) "**Can communication-and-resolution programs achieve their potential? Five key questions**" in Health Affairs.
- Published (with McDonald TB, Van Niel M, Gocke H, Tarnow D, Hatlie M) "**Implementing communication and resolution programs: Lessons learned from the first 200 hospitals**" in the Journal of Patient Safety and Risk Management.

2018-2019 FACULTY HIGHLIGHTS



NANCY JECKER, PhD PROFESSOR

- Completion of a new book entitled “**Ending Midlife Bias: New Values fit Old Age**” (Oxford University Press).
- Received an International Fellowship from the **Japanese Society for the Promotion of Science**.
- Submitted an application for a **Fulbright Fellowship**.
- Created a new course “**Global Perspectives on Bioethics**” in collaboration with the UW Department of Global Health.

HELENE STARKS, PhD ASSOCIATE PROFESSOR



- Launched an **expansion of the Graduate Certificate in Palliative Care** to train faculty in Portland, Oregon to develop a pediatric-specific track and a primary care-specific track. This expansion means that future cohorts of participants will get to choose between 3 options for the in-person learning experiences that will better match their practice environments. It also builds teaching capacity in regional hubs.
- Launched a new research study to **evaluate diabetes curricula in high school biology and health classes**.
- Co-authored publications from California about the **implementation of the End of Life Options act** to summarize hospital policies on how to implement the 2016 law that provides access to medical aid in dying.

PROGRAM HIGHLIGHTS

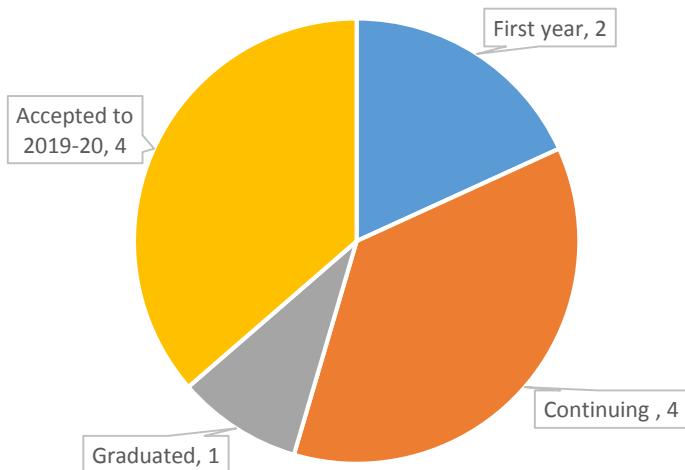


2018-2019

Academic Programs

Master's Program

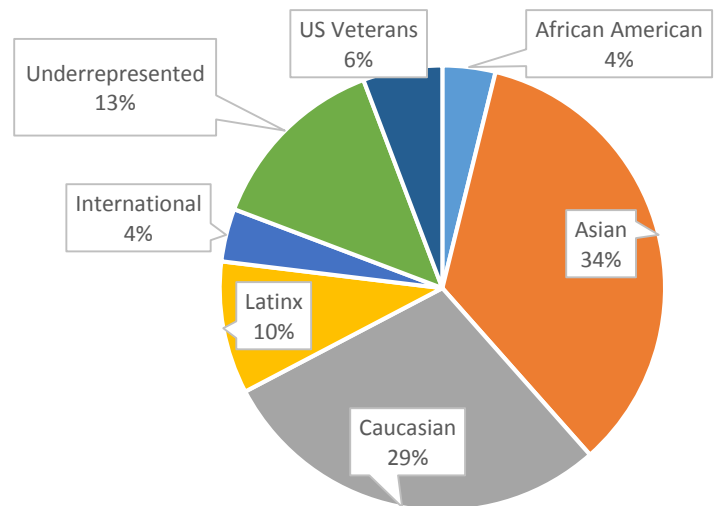
6 graduate students pursued their Master's of Arts in Bioethics in 2018-2019.



Minor Program

42 undergraduate students declared a Minor in Bioethics in 2018-2019.

Minor Diversity Demographics



PROGRAM HIGHLIGHTS

2018-2019

Bioethics Training Programs



- In 2018, the Department's **UW Biomedical Research Integrity Program** hosted 668 trainees for five lectures and 81 discussion groups. These activities fulfill the contact hours for **NIH's annual Responsible Conduct of Research training requirement**.
- The Department launched its new **Advanced Training in Healthcare Ethics online certificate program** with nine students this academic year!
- The 31st **Summer Seminar in Healthcare Ethics Conference** was held 7/30-8/3/18 and hosted 97 attendees.
- The 2nd annual **Surgical Ethics Day Conference** was held 8/3/18 and hosted 22 attendees.
- Founded **the Bodemer Interprofessional Ethics Labs**, collaboratively sponsored by the Bodemer Endowed Lectureship and The UW Center for Health Sciences Interprofessional Education Research and Practice, to promote **discussion-based learning of current ethical issues** in healthcare and science. Two events were held this year, reaching more than 150 UW students, faculty, and staff.



EVENT HIGHLIGHTS

UW Medicine
Bioethics & Humanities

BIOETHICS GRAND ROUNDS

ethics | biology | medicine | philosophy | social determinants | politics | culture | life sciences | biotechnology | law

What gives them the right?

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Legal privilege and waivers of consent for research

Waivers of informed consent for research are permitted in the United States under the Common Rule, HIPAA regulations, and the FDA's Exception from Informed Consent rule for emergency research.

Friday, October 12, 2018
11 am to 12 pm
Health Sciences T-473

Discussion objectives:

- Assess what legal right researchers have to carry out research procedures without the permission of subjects
- Discuss whether it is reasonable to believe that subjects from whom no consent is sought would agree, if asked
- Review what is known about participation and refusal rates in US-based research
- Address necessity for justification of waivers in terms of the social utility and acceptability of research

Guest Speaker: Jon F. Merz, MBA, JD, PhD
Associate Professor, Dept. of Medical Ethics & Health Policy
Perelman School of Medicine at the University of Pennsylvania



ORGANIZED BY: James Kirkpatrick, MD, Chair of the UWMC Ethics Committee

The University of Washington School of Medicine is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians. The University of Washington School of Medicine designates this live activity for a maximum of 6.0 AMA PRA Category 1 Credits. Physicians should claim only the credit commensurate with the extent of their participation in the activity. (Each session 1.0 credit.)


UW Medicine
Bioethics & Humanities

BIOETHICS GRAND ROUNDS

ethics | biology | medicine | philosophy | social determinants | politics | culture | life sciences | biotechnology | law

Is Death Relative?

Navigating the Clinical Complexities Surrounding Brain Death



Discussion objectives:

- Identify ethical controversies surrounding brain death.
- Describe practical aspects of brain death determination.
- Discuss multi-disciplinary strategies to respectfully and professionally support families experiencing brain death of a loved one.

Monday, November 5, 2018
4:30-5:30 pm
Plaza Café Conference Room A/B


Panelists



Claire Creutzfeldt, MD
Assistant Professor
Neurology




James A. Fausto, MD
Associate Professor
Family Medicine
Medical Director, Palliative Care
UW Medical Center



Denise M. Dudzinski, PhD, MTS
Professor and Chair
Bioethics & Humanities

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INTERPROFESSIONAL ETHICS LAB: NAVIGATING COMPLEXITIES IN BRAIN DEATH



It's a Night of Bioethics (and Pizza!)

We invite students in the healthcare profession (MSW, MPH, MD, DO, PharmD, BSN, DNP) to join the Department of Bioethics & Humanities and the Center for Health Sciences Interprofessional Education, Research & Practice for dinner and an evening of connecting with colleagues and engaging in ethical dilemmas!


In this lab, we will focus on applying some key approaches of clinical ethics to a case of conflict around the declaration of brain death. Ethics Consultants and clinicians from UWMC and HMC will help guide small group discussion using some of the language, principles, and tools that guide bioethicists.

Learning Objectives

- Learn about topic-specific principles of ethics and how they can be used to analyze a case of ethical conflict or uncertainty.
- Work as a collaborative team to apply ethics analysis tools to the healthcare decision-making process.

When: September 27, 2018, 5:30-7:30pm
Where: Pacific Room, Health Sciences Building
UW School of Medicine
Please RSVP by Sep 15, 2018: kaybrke@uw.edu
Contact: kaybrke@uw.edu

The Bodemer Interprofessional Ethics Lab: Navigating Patients' Refusals of Care



- Are you curious about how to work across differences between patients and health care teams?
- Are you interested in learning about practical approaches to ethical decision-making in clinical settings?
- Are you a health profession student looking for opportunities to learn alongside other health professions?

Join us for a night of bioethics (and dinner!)

When: Tuesday January 8, 2018, 6:00-8:00pm (food at 5:30pm!)

SCHOLARSHIP HIGHLIGHTS



Book Chapters

Blacksher E. 2018. Social values as social determinants of health. Plough AL, ed. *Advancing Health and Well-Being: Using Evidence and Collaboration to Achieve Health Equity* New York, NY: Oxford University Press, 2018.

Blacksher E. 2018. Public Health and social justice: An argument against stigma as a tool of health promotion and disease prevention. In *The Handbook of Stigma, Discrimination and Health*, Link B, Dovidio J, Major B., eds. New York, NY: Oxford University Press.

Campelia, GD, DM Dudzinski. 2019. "History and Development of Medical Ethics in the West", In *Surgical Ethics*, Ed. A. Ferreres, Springer Nature, p. 3-15.

Campelia, GD & DM Dudzinski. 2018. History & Development of Medical Ethics in the West. *Surgical Ethics: Principles & Practice*. Springer Science. [invited original work]



SCHOLARSHIP

Commentaries, Editorials & Letters

- Akabayashi A, Nakazawa E, Jecker NS, 2019, “The World’s First Clinical Trial for Aplastic Anemia Patient with Thrombocytopenia Administering Platelets Generated from Autologous iPS Cells (Induced Pluripotent Stem Cell)” (Letter to The Editor). *International Journal of Hematology* 109: 239-240, at: <https://doi.org/10.1007/s12185-018-02565-y>
- Akabayashi A, Nakazawa E, Jecker NS, 2018. “Japan must tighten up clinical trial of stem cells for heart failure.” *Correspondence. Nature* 560: 431.
- Dudzinski, DM. White privilege & Playing it Safe. *Bioethics.net* blog. April 11, 2018. <http://www.bioethics.net/2018/04/white-privilege-playing-it-safe/> [online commentary]
- Fullerton, S & Rohlf, R (2018). Should police detectives have total access to public genetic databases? *LeapsMag*, July 23, <https://leapsmag.com/should-police-detectives-have-total-access-to-public-genetic-databases/> [commentary].
- Kon, A & DM Dudzinski. 2019. Navigating End-of-Life Decisions Using Informed Nondissent. *American Journal of Bioethics* March 21. <https://doi.org/10.1080/15265161.2018.1563652> [commentary]
- Lee HH, Blacksher E, Burke W. Authors’ response: Sedation Safety Has Many Perspectives, and the Discussion Is Ongoing. *Pediatrics* 2018;141(5):2. DOI:10.1542/peds.2018-0257A
- Murray, MF, Evans, JP, Angrist, M, Chan, K, Uhlmann, W, Doyle, DL, Fullerton, SM, Ganiats, T, Hagenkord, J, Imhof, S, Rim, SH, Ortmann, L, Aziz, N, Dotson, WD, Matloff, E, Young, K, Kaphingst, K, Bradbury, A, Scott, J, Wang, C, Zauber, A, Levine, M, Korf, B, Leonard, D, Wicklund, C, Isham, G & Khoury, MJ (2018). A proposed approach for implementing genomics-based screening programs for healthy adults. *NAM Perspectives*. Discussion Paper, National Academy of Medicine, Washington, DC. <https://doi.org/10.31478/201812a> [commentary/collaboration].
- Starks H, Griswold J, Munn M. Becoming a GEMNet Affiliate Investigator. Research ethics training module for teachers serving as site investigators. <https://youtu.be/VIS7QuoVFsY> March 2018.



SCHOLARSHIP

Peer-Reviewed Papers (1 of 6)

- Adams C, Blacksher E, Burke W. Using the Precautionary Principle to Motivate Shared Responsibility for Shift Work. *Public Health Ethics* 2019;12(1):1-10. doi:10.1093/phe/phy005
- Akabayashi A, Nakazawa E, Ino H, Ozeki-Hayashi R, Jecker NS, 2018, "Sacrificing the Fukushima 50 Again?" *Journal of Public Health* 40(2): 1-4, doi:10.1093/pubmed/fdy143
- Akabayashi A, Nakazawa E, Jecker NS, 2018, "Endangerment of the iPSC (Induced Pluripotent Stem Cell) Stock Project in Japan: On the Ethics of Public Funding Policies." *Journal of Medical Ethics*, Epub ahead of print: DOI:10.1136/medethics-2018-105024
- Akabayashi A, Nakazawa E, Jecker NS, 2019. "Adhering to Ethical Benchmarks in Neurology Clinical Trials Using iPSCs." *Neurotherapeutics*, First Online 28 March 2019. DOI: <https://doi.org/10.1007/s13311-019-00728-1>
- Amendola, LA, Berg, JS, Horowitz, CR, Angelo, F, Bensen, JT, Biesecker, BB, Biesecker, LG, Cooper, GM, East, K, Filipowski, K, Fullerton, SM, Gelb, BD, Goddard, KAB, Hailu, B, Hart, R, Hassmiller-Lich, K, Joseph, G, Kenny, EE, Koenig, BA, Knight, S, Kwok, PY, Lewis, KL, McGuire, AL, Norton, ME, Ou, J, Parsons, DW, Powell, BC, Risch, N, Robinson, M, Rini, C, Scollon, S, Slavotinek, AM, Veenstra, DL, Wasserstein, MP, Wilfond, BS, Hindorff, LA on behalf of the CSER consortium, Plon, SE, & Jarvik, GP (2018). The Clinical Sequencing Evidence-Generating Research (CSER) consortium: integrating genomic sequencing in diverse and medically underserved populations. *American Journal of Human Genetics*, 103(3): 319-327.
- Antommaria, AHM, Brothers, KB, Myers, JA, Feygin, YB, Aufox, SA, Brilliant, MH, Campos, D, Carrell, DS, Connolly, J, Conway, P, Fullerton, SM, Garrison, NA, Horowitz, CR, Jarvik, GP, Kaufman, Kitchner, TE, Li, R, Ludman, EJ, McCarty, CA, McCormick, JB, McManus, VD, Mercaldo, ND, Myers, MF, Sanderson, SC, Scrol, A, Williams, JL, Shrubsole, MJ, Schildcrout, JS, Smith, ME, Clayton, EW, & Holm, IA (2018). Parental attitudes toward consent and data sharing in biobanks: a multi-site experimental survey. *AJOB Empirical Ethics*, 21: 1-15.
- Bisailon L, Cattapan A, Anton L, Driessen A, van Duin E, SpruitS, Jecker NS, Forthcoming. "Using the Tools of Social Science, Friendship, and Conversation: Doing Academia Differently." *Feminist Studies*.
- Blacksher E. Response to Commentaries on "Shrinking Poor White Life Spans." *American Journal of Bioethics* 2018;18(11):W1-W4. doi:10.1080/15265161.2018.1523506
- Blacksher E. Shrinking Poor White Life Spans: Class, Race, and Health Justice. *American Journal of Bioethics* (target article, 10 commentaries) 2018;18(10):3-14. doi:10.1080/15265161.2018.1513585
- Blacksher E. 2018. Social values as social determinants of health. Plough AL, ed. *Advancing Health and Well-Being: Using Evidence and Collaboration to Achieve Health Equity* New York, NY: Oxford University Press, 2018.



SCHOLARSHIP

Peer-Reviewed Papers (2 of 6)

- Bowen, DJ Quintiliani, L, Goodman, R, Smith, E. (2018) Changing the housing environment to reduce obesity in public housing residents: A cluster randomized trial, in press, BMC Public Health, e ahead of print..
- Bowen, DJ, Meischke, H., Painter, Doll, A., Hyams, T, Eisenberg, M Development of an implementation index for community change to improve out-of-hospital cardiac arrest In press, Heart and Lung.
- Bowen, DJ, Hay, J, Meischke, H, Mayer, JA, Harris-Wai, J, Burke, W. Randomized trial of a web-based survivor intervention on melanoma prevention behaviors of first degree relatives, in press, Cancer Causes and Control., 2018, epub ahead of print. .
- Bowen, DJ, Hyams, T, Laurino, M, Woolley, T, Cohen, S, Jarvik, G, Leppig, K.. Jarvik, G Development of FamilyTalk: An intervention to support communication and educate families about colorectal cancer risk, in press, Journal of Cancer Education.
- Cain CL, Koenig B, Starks H, Thomas J, Forbes L, McCleskey S, Wenger NS. Hospital responses to the End of Life Option Act: Implementation of aid in dying in California. JAMA Internal Medicine. 2019; in press. Epub ahead of print. doi:10.1001/jamainternmed.2018.8690.
- Campelia, G., and T. Tate. Forthcoming March/April 2019. "Empathic Practice: The Struggle & Virtue of Empathizing with a Patient's Suffering", Hastings Center Report. [original work]
- Coughlin SS, Williams V, Moore N, Bowen D, Anglin J, Mansur N, De Leo G. The Augusta, Georgia Breast Cancer Survivor Study J Cancer Treat & Diagnosis. (2018); 2(3): 10-15.
- Dudzinski, DM, C Mahr, J Bjelkengren, N. Mokadam. 2019. The Ethical Conundrum: Conflicting Advocacy Positions in Advanced Heart Failure Therapy. Clinical Transplantation. March 19 DOI: 10.1111/ctr.13489 [original work]
- Edwards, KL, Goodman, D, Johnson, CO, Wenzel, L, Condit, C, Bowen DJ. (2018) Controversies among cancer registry participants, genomic researchers, and institutional review boards about returning participants' genomic results, Public Health Genomics, e ahead of print.
- Enzler, C, Bowen, DJ, Jabson, J, and Hanson, AA. Comparing provider and patient views of issues for low resourced breast cancer patients, in press, PsychoOncology.
- Fisher KA, Smith KM, Gallagher TH, Huang JC, Borton JC, Mazor KM. We want to know: patient comfort speaking up about breakdowns in care and patient experience. In press, BMJ Qual Saf.
- Fullerton, S & Rohlfs, R (2018). Should police detectives have total access to public genetic databases? LeapsMag, July 23, <https://leapsmag.com/should-police-detectives-have-total-access-to-public-genetic-databases/>.



SCHOLARSHIP

Peer-Reviewed Papers (3 of 6)

- Gallagher TH, Mello MM, Sage W, Bell SK, McDonald TB, Thomas EJ. Can communication-and-resolution programs achieve their potential? Five key questions. *Health Aff (Milwood)*. 2018;37(11):1845-1852.
- Goodman D, Bowen D, Wenzel L, Tehrani P, Fernando F, Khacheryan A, Chowdhury F, Johnson CO, Edwards K. The research participant perspective related to the conduct of genomic cohort studies: A systematic review of the quantitative literature. *Transl Behav Med*. 2018 Jan 29;8(1):119-129. PMID: 29385589
- Goodman D, Johnson CO, Bowen D, Smith M, Wenzel L, Edwards KL. A comparison of views regarding the use of de-identified data. *Transl Behav Med*. 2018 Jan 29;8(1):113-118.
- Heath, L, Gray, SL, Boudreau, DM, Thummel, K, Edwards, KL, Fullerton, SM, Crane, PK, & Larson EB (2018). Cumulative antidepressant use and risk of dementia in a prospective cohort study. *Journal of the American Geriatrics Society*, 66(10): 1948-1955.
- Henrikson, NB, Blasi, PR, Fullerton, SM, Grafton, J, Leppig, KA, Jarvik, GP, & Larson, EB (2019). "It would be so much easier:" Health system-led genetic risk notification: feasibility and acceptability of cascade screening in an integrated system. *Journal of Community Genetics*, doi: 10.1007/s12687-019-00412-z.
- Horowitz, CR, Orlando, LA, Sanderson, SC, Slavotinek, AM, Hart, R, Bonham, VL, Peterson, J, Angelo, F, Biesecker, B, Cameron, LD, Fullerton, SM, Gelb, BD, Goddard, KAB, Hindorff, LA, Jarvik, GP, Kenny, EE, Knight, S, Korf, BR, Kaufman, D, Madden, E, McGuire, AL, Ou, J, Wasserstein, MP, Robinson, M, & Leventhal, H. (in press) A conceptual framework for conducting genomic medicine research: GMER (Genomic Medicine Research) Framework. *American Journal of Human Genetics*.
- Jecker NS, 2018 Forthcoming. "Growing Older and Getting Wiser: Lessons from Japan." *The International Journal of Applied Philosophy*.
- Jecker NS, 2018, "Age-Related Inequalities in Health and Healthcare: The Life Stages Approach." *Developing World Bioethics* 18: 144-155
- Jecker NS, 2018. "Pfizer's Corporate Citizenship," *American Journal of Bioethics* 18(11): 18-20
- Jecker NS, Chin JJ-L, 2018, "Justice and Global Care Chains: Lessons from Singapore." *Developing World Bioethics*, Epub ahead of print: DOI: 10.1111/dewb.12213: 1-14
- Jecker NS, Miwa E, 2019, "What Do We Owe the Newly Dead: An Ethical Analysis of Findings from Japan's Corpse Hotels Workers," *Bioethics*, DOI: 10.1111/bioe.12578
- Jecker NS, Wightman AG, Rosenberg AR, Diekema DS, 2018, "Ethical Guidance for Selecting Clinical Trials to Receive Limited Space in an Immunotherapy Production Facility." *American Journal of Bioethics* 18(4): 55-64



SCHOLARSHIP

Peer-Reviewed Papers (4 of 6)

- Jecker NS, Wightman AG, Rosenberg AR, Diekema DS, 2018, "Fairly Allocating Space in an Immunotherapy Production Facility: Reply to Critics." *American Journal of Bioethics* 18(5): W9-W12
- Jecker NS, Wightman, AG, Rosenberg AR, 2018. "Ethical Guidance for Selecting Clinical Trials to Receive Limited Space in an Immunotherapy Production Facility." *American Journal of Bioethics*.
- Jecker NS, Wightman, AG, Rosenberg AR, 2018. "Fairly Allocating Space in an Immunotherapy Production Facility: Reply to Critics." *American Journal of Bioethics*.
- Jecker NS, Wightman, AG, Rosenberg AR, 2018. Jecker NS., 2018. "Negotiating Scarce Resources in Clinical Research: The Case of Spinal Muscular Dystrophy and Nusinersen." *American Journal of Bioethics* 18(5): W9-W12.
- Korngiebel D, Zech J, Chappelle A, Burke W, Carline J, Gallagher TH, Fullerton S. Practice implications of expanded genetic testing in oncology. In press, *Cancer Investigation*. 2019.
- Korngiebel, DK, Zech, JM, Chappelle, A, Burke, W, Carline, JD, Gallagher, TH, & Fullerton, SM (2019). Practice implications of expanded genetic testing in oncology. *Cancer Investigation*, DOI: 10.1080/07357907.2018.1564926.
- Langer, SL, Soltero, EG, Beresford, SAA, McGregor, B, Albano, D, Patrick, DL, and Bowen, DJ. Socioeconomic status differences in food consumption following a laboratory-induced stressor, *Health Psychology Open*, 2018, 1-9.
- Lee, SSJ, Fullerton, SM, Saperstein, A, & Shim, J. The ethics of inclusion: cultivating trust in precision medicine. Revised and resubmitted to *Science* on March 12, 2019.
- Lepoire, E, Basu, B, Bowen, DJ, Walker, L. What do people think about genetics? A systematic review, *Journal of Community Genetics*, 2018, epub ahead of print..
- Li, M, Bennette, CS, Amendola, LM, Hart, MR, Heagerty, P, Comstock, B, Tarczy-Hornoch, P, Fullerton, SM, Regier, DA, Burke, W, Trinidad, SB, Jarvik, GP, Veenstra, DL, & Patrick, DL (2018). The Feelings About genomiC Testing Results (FACToR) questionnaire: preliminary development and validation. *Journal of Genetic Counseling*, doi: 10.1007/s10897-018-0286-9.
- MacKay D, Jecker NS, Pitisuttithum P, Saylor K. Forthcoming. "A Justice Framework for Human Challenge Studies and Emerging Infectious Disease." *Bioethics*.
- Makhnoon S, Lauren G, Burke W, Bowen JD, Shirts BH. Experiences of Patients Seeking to Participate in Variant of Uncertain Significance Reclassification Research, *J Genet Couns*. 2019;1-13.
- Makhnoon S, Shirts BH, Bowen DJ, Fullerton SM. Hereditary cancer gene panel test reports: wide heterogeneity suggests need for standardization. *Genetics in Medicine*. 2018 doi:10.1038/gim.2018.23 PMID: 29493582



SCHOLARSHIP

Peer-Reviewed Papers (5 of 6)

- Mazor KM, Kamineni A, Roblin DW, Anau J, Robinson BE, Dunlap BS, Firreno C, Gallagher TH. Encouraging patients to speak up about problems in cancer care. *Journal of Patient Safety*. Epub ahead of print, 2018.
- McDonald TB, Van Niel M, Gocke H, Tarnow D, Hatlie M, Gallagher TH. Implementing communication and resolution programs: Lessons learned from the first 200 hospitals. *Journal of Patient Safety and Risk Management*. 2018;23(2) 73-78.
- Mendonca VS, Gallagher TH, de Oliveira RA. The function of disclosing medical errors: New cultural challenges for physicians. *HEC Forum*. Epub ahead of print, 2018.
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SCHOLARSHIP

Peer-Reviewed Papers (6 of 6)

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- Taliun, D, et al. [200+ authors]. Sequencing of 53,831 diverse genomes from the NHLBI TOPMed program. Resubmitted to Nature on February 22, 2019.
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- Young, B, Blacksher, E, Cavanaugh, K, Freedman, BI, Fullerton, SM, Kopp, JB, Umeukeje, E, West, KM, Wilson, JG, & Burke, W. APOL1 testing in African Americans: involving the community in policy discussions. Submitted to Annals of Internal Medicine on March 13, 2019.



2018-2019 STAFF HIGHLIGHTS



Susan Brown
Trinidad, MA,
Senior Research
Scientist

- Published (with Shaw JL, Dirks L, Ludman EJ, Burke W, Dillard DA) **“Perceptions of alcohol misuse among Alaska Native healthcare system stakeholders: a qualitative exploration”** in the Journal of Ethnicity in Substance Abuse.
- Published (with Beima-Sofie KM, Ngunjiri K, Heffron R, Baeten J, John-Stewart GC, Kelley MC) **“Lessons from PrEP: how experts weigh ethics and evidence when evaluating HIV-prevention medications for use in pregnant women”** in AIDS and Behavior.
- Published (with Li M, Bennette CS, Amendola LM, Hart MR, Heagerty P, Comstock B, Tarczy-Hornoch P, Fullerton SM, Regier DA, Burke W, Jarvik GP, Veenstra DL, Patrick DL) **“The Feelings About genomic Testing Results (FACToR) Questionnaire: preliminary development and validation”** in the Journal of Genetic Counseling.
- Presented as an invited panelist at Oxford University’s **“REACH: Resilience, empowerment, and advocacy in women’s and children’s health research, an international collaborative study in research ethics,”** which was sponsored by The Wellcome Trust and MRC Newton Fund.

FINANCE & ADMINISTRATION HIGHLIGHTS

- Launched a new department website
- Created an electronic sign-in and automated survey system for the UW Biomedical Research Integrity Program
- Facilitated the crafting a new departmental Mission Statement: Health through Social Justice
- Began work on a self-service Grant Tracking tool with the Department of Global Health



