

17 August 2020

CURRICULUM VITAE

JOSEPH ALI

PERSONAL DATA

Johns Hopkins Berman Institute of Bioethics
Johns Hopkins Bloomberg School of Public Health
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EDUCATION AND TRAINING

Degree	Year	Institution	Field
Juris Doctorate (JD)	2006	University of Pittsburgh School of Law, USA	Law
Certificate of Advanced Study	2006	University of Pittsburgh School of Law, USA	Health Law
Honours Bachelor of Arts (HonBA)	2003	University of Toronto, Canada	Bioethics; Philosophy

Medical or Other Licensure

Licensed Attorney – District of Columbia (2008-present)
Licensed Attorney – Commonwealth of Pennsylvania (2007-present)

PROFESSIONAL EXPERIENCE

Assistant Professor, 2018 – present, Johns Hopkins Bloomberg School of Public Health, Department of International Health
Associate Director, Global Programs (Core Faculty), 2018 – present, Johns Hopkins Berman Institute of Bioethics
Faculty, 2018 – present, Johns Hopkins Bloomberg School of Public Health, Center for Humanitarian Health
Co-Chair, Ethics and Regulatory Work Group, 2018 – present, NIH/VA/DOD Pain Management Collaboratory Coordinating Center
Associate Faculty, 2017 – 2018, Johns Hopkins Bloomberg School of Public Health, Department of Health and Policy Management
Research Scholar II (Core Faculty), 2016 – 2018, Johns Hopkins Berman Institute of Bioethics

Associate Faculty, 2015 – 2018, Johns Hopkins Bloomberg School of Public Health, Department of International Health
Research Scholar (Core Faculty), 2009 – 2015, Johns Hopkins Berman Institute of Bioethics
Co-Lead, Ethics & Regulatory Task Force, 2013-2015, The National Patient-Centered Clinical Research Network (PCORnet), Patient Centered Outcomes Research Institute (PCORI)
Senior Administrative Coordinator, 2008-2009, Johns Hopkins Berman Institute of Bioethics & Bloomberg School of Public Health, Dept. of Health and Policy Management
Administrative Coordinator, 2007-2008, Johns Hopkins Berman Institute of Bioethics & Bloomberg School of Public Health, Dept. of Health and Policy Management
Research Staff, 2005-2006, University of Pittsburgh Center for Bioethics & Health Law
Certified Legal Practitioner, 2005, University of Pittsburgh Civil Practice Health Law Clinic
Faculty Research Fellow, 2004-2005, University of Pittsburgh School of Law
Legal Intern, Attorney General Recruit, 2004, Alabama Department of Public Health, Office of General Counsel

PROFESSIONAL ACTIVITIES

Society Membership and Leadership

Member – International Association of Bioethics (2016-present)
Member – Health Systems Global, Ethics Thematic Working Group (2015-present)
Member – American Society for Bioethics & Humanities (2003-07, 2019)
Member – American Bar Association (2008-10)
Member – Pennsylvania Bar Association (2007-10)
Member – Society for Social Studies of Science (2006)
Officer – Health Law Society, University of Pittsburgh School of Law (2004-05)
Member – Asian Law Society, University of Pittsburgh School of Law (2003)
Philosophy Course Union Representative – University of Toronto (2000-01)

Participation on Advisory Panels

Member - Public Health, Surveillance, and Human Rights Network; Social Science Research Council (2020-present)
Member – Working Group – World Health Organization (WHO), Measuring Quality of Research Ethics Oversight (2019-present)
Member – Steering Committee – NIH/VA/DOD Pain Management Collaboratory (2018-present)
Member – IRB Workgroup – The National Patient-Centered Clinical Research Network (PCORnet), Patient Centered Outcomes Research Institute (PCORI) (2015-2018)
Member – Working Group – Users’ Guide for Integrating Patient Reported Outcomes into Electronic Health Records (PRO-EHR) (2016-17)

Member – Stakeholder Panel – Patient-Centered Outcomes Research Oversight Study (2015-17)
Member – Organizing Committee – NIH Health Care Systems Research Collaboratory, Ethics in Pragmatic Clinical Trials Workshop (2015-16)
Member – American Bar Association (ABA) Advisory Panel (2012-14)

Program or Project Development/Leadership

Co-lead – Oxford Wellcome Centre-Johns Hopkins Berman Institute Collaborative Bioethics Research and Training Program
Director – JHU-Addis Ababa University Research Ethics Training Program
Associate Director – JHU-University of Malaya, Master of Research Ethics Studies Program
Director – JHU Global Bioethics Training Program (month-long intensive)
Executive Committee – Johns Hopkins-Fogarty African Bioethics Training Program
Co-developer – African Bioethics Consortium
Director – JHU Global Bioethics Program Webinar Series
Co-developer – Master of Bioethics (MBE) Program, JHSPH/Berman Institute
Co-developer – Berman Institute Bioethics Intensives Program (JHU Summer Institute)

Consultations

Univ. of Minnesota/ Hennepin County Medical Center - COMPUTE 2.0 study (2019)
World Health Organization (WHO), Geneva, Switzerland (2015, 2019)
Center for Medical Technology Policy, Baltimore, MD (2009)

PEER REVIEW & EDITORIAL ACTIVITIES

Peer Review (Journals/Publishers)

Accountability in Research: Policies and Quality Assurance
American Journal of Bioethics: Primary Research
Annals of Internal Medicine
Bulletin of the World Health Organization
British Medical Journal
BMC Medical Ethics
Canadian Journal of Bioethics
Developing World Bioethics
Global Health: Science and Practice
IRB Ethics & Human Research
Journal of Empirical Research on Human Research Ethics
National Academies of Sciences, Engineering, and Medicine, Division of Behavioral and Social Sciences and Education
Philosophy, Ethics & Humanities in Medicine
Pittsburgh Journal of Environmental & Public Health Law
PLOS One

Trials
University of Toronto Journal of Bioethics
SAGE Publications (book)
Rutgers University Press (book)

Editorial Service

Editorial Board Member – Accountability in Research: Policies and Quality Assurance (2015-present)
Guest Editor – Special issue on research ethics in Africa, *Global Bioethics* (2018-19)
Articles Editor – Special issue on global trauma and injury research, *Surgery* (2016)
Co-Founder & Executive Editor – Pittsburgh Journal of Environmental & Public Health Law, University of Pittsburgh School of Law (2005-06)
Editorial Board Member – University of Toronto Journal of Bioethics (2002-03)

Research Study Sections and Proposal Review

Study Section Member – U.S. Department of Defense – Congressionally Directed Medical Research Programs (CDMRP)
Ad Hoc Reviewer – U.K. Wellcome Trust (multiple proposals)

Support to Professional Conferences

Abstract Reviewer and Oral Session Curator – Sixth Global Symposium on Health Systems Research (HSR 2020), Dubai, U.A.E., subtheme on ‘the innovation environment, ethical and legal implications’

HONORS AND AWARDS

Honors

Named one of ‘10 People to Watch Under 30’ – B Magazine, Baltimore, MD (2011)
Recognized for top performance in Health Law & Policy course, University of Pittsburgh School of Law (2006)
Recognized for ‘Excellence in Teaching’ by students at Johns Hopkins Bloomberg School of Public Health

- Fogarty Bioethics Fellows Seminar (Term 3, 2020)
- Fogarty Bioethics Fellow Seminar (Term 1, 2019)
- Introduction to Ethics of U.S. And International Human Subject Research (Summer 2019)

Awards

Staff Recognition Award – Johns Hopkins Bloomberg School of Public Health (2009)

PUBLICATIONS

(* = mentee/trainee)

Peer-Reviewed Journal Articles

1. "Adaptation of a mobile phone health survey for risk factors for noncommunicable diseases in Colombia: a qualitative study" *Global Health Action* (in press).
2. Limaye RJ, Sauer M, **Ali J**, Bernstein J, Wahl B, Barnhill A, Labrique A. "Building trust while influencing online COVID-19 content in the social media world" *The Lancet Digital Health*. 2020 Jun 1;2(6):e277-8.
3. Ho CW, **Ali J**, Caals K. "Ensuring trustworthy use of artificial intelligence and big data analytics in health insurance" *Bulletin of the World Health Organization*. 2020 Apr 1;98(4):263.
4. Rutebemberwa E, Namutundu J, Gibson DG, Labrique AB, **Ali J**, Pariyo GW, Hyder AA. "Perceptions on using interactive voice response surveys for non-communicable disease risk factors in Uganda: a qualitative exploration" *mHealth* 2019;5:32.
5. Kerns RD, Brandt CA, Peduzzi P, **NIH-DoD-VA Pain Management Collaboratory**. "NIH-DoD-VA Pain Management Collaboratory" *Pain Medicine* 2019;pnz186, <https://doi.org/10.1093/pm/pnz186> (Contribution as member of NIH-DoD-VA Pain Management Collaboratory).
6. Mwaka E, Nakigudde J, **Ali J**, Ochieng J, Hallez K, Tweheyo R, Labrique A, Gibson DG, Rutebemberwa E, Pariyo G. "Consent for mobile phone surveys of non-communicable disease risk factors in low-resource settings: an exploratory qualitative study in Uganda" *mHealth* 2019;5:26.
7. Gibson DG, Wosu A, Pariyo G, Ahmed S, **Ali J**, Labrique AS, Khan IA, Rutebemberwa E, Flora MS, Hyder A. "Effect of airtime incentives on response and cooperation rates in noncommunicable disease interactive voice response surveys: randomised controlled trials in Bangladesh and Uganda" *BMJ Global Health* 2019;4:e001604.
8. Bernstein J, Holroyd TA, Atwell JE, **Ali J**, Limaye RJ. "Rockland county's proposed ban against unvaccinated minors: Balancing disease control, trust, and liberty" *Vaccine* 2019 Jun 10.
9. DiStefano MJ, Rivera YM, Thrul J, **Ali J**. "Promoting justice in locating and tracking research participants through social media" *The American Journal of Bioethics* 2019 19:6, 71-73, DOI: 10.1080/15265161.2019.1602187
10. Pariyo GW, Greenleaf AR, Gibson DG, **Ali J**, Selig H, Labrique AB, Al Kibria GM, Khan IA, Masanja H, Flora MS, Ahmed S. "Does mobile phone survey method matter? Reliability of computer-assisted telephone interviews and interactive voice response non-communicable diseases risk factor surveys in low and middle income countries" *PLoS One* 2019 Apr 10;14(4):e0214450.
11. Ntseane DM*, **Ali J**, Hallez K, Mokgweetsi B, Kasule M, Kass NE. "The features and qualities of online training modules in research ethics: a case study evaluating their

- institutional application for the University of Botswana” *Global Bioethics* 2019, DOI: 10.1080/11287462.2019.1592305.
12. **Ali J**, DiStefano MJ, Coates McCall I, Gibson DG, Al Kibria GM, Pariyo GW, Labrique AB, Hyder AA. “Ethics of mobile phone surveys to monitor non-communicable disease risk factors in low-and middle-income countries: A global stakeholder survey” *Global Public Health* 2019 Jan 11:1-5.
 13. Hyder A, Selig H, **Ali J**, Rutebemberwa E, Islam K, Pariyo G. “Integrating capacity development during digital health research: a case study from global health, *Global Health Action* 2019 12:1, 1559268, DOI: 10.1080/16549716.2018.1559268.
 14. Gensheimer SG, Wu AW, Snyder CF, PRO-EHR Users’ Guide Steering Group, **PRO-EHR Users’ Guide Working Group**. “Oh, the Places We’ll Go: Patient-Reported Outcomes and Electronic Health Records.” *The Patient-Patient-Centered Outcomes Research*. 2018 Dec 1;11(6):591-8. (contribution as member of PRO-EHR Users’ Guide Working Group)
 15. Deutsch-Feldman M, **Ali J**, Kass N, Phaladze N, Michelo C, Sewankambo N, Hyder A. “Improving institutional research ethics capacity assessments: lessons from sub-Saharan Africa” *Global Bioethics* 2018, DOI: 10.1080/11287462.2018.1528660.
 16. Zulu JM*, **Ali J**, Hallez K, Kass N, Michelo C, Hyder A. “Ethical challenges in research on post-abortion care with adolescents: experiences of researchers in Zambia” *Global Bioethics* 2018, DOI: 10.1080/11287462.2018.1528657.
 17. Mweemba C*, **Ali J**, Hyder A. “Providing monetary and non-monetary goods to research participants: perspectives and practices of researchers and Research Ethics Committees in Zambia” *Global Bioethics* 2018.
<https://doi.org/10.1080/11287462.2018.1527672>
 18. Zulu JM*, **Ali J**, Hallez K, Kass N, Michelo C, Hyder A. “Ethics challenges and guidance related to research involving adolescent post-abortion care: a scoping review” *Reproductive Health* 2018; 15:71 <https://doi.org/10.1186/s12978-018-0515-6>
 19. Hyder A, Deutsch-Feldman M, **Ali J**, Sikateyo B, Kass N, Michelo C. “Rapid Assessment of Institutional Research Ethics Capacity: A Case Study from Zambia” *Acta Bioethica* 2017; 23 (1): 35-46.
 20. Pratt B, Paul A, Hyder A, **Ali J**. “Ethics of health policy and systems research: A scoping review of the literature” *Health Policy Planning* 2017 czx003. doi: 10.1093/heapol/czx003
 21. Yakubu A*, Hyder A, **Ali J**, Kass N. “Research Ethics Committees in Nigeria: A survey of operations, functions and needs” *IRB: Ethics & Human Research* 2017;39(3):11-19.
 22. **Ali J**, Labrique AB, Gionfriddo K, Pariyo G, Gibson DG, Pratt B, Deutsch-Feldman M, Hyder AA “Ethics Considerations in Global Mobile Phone-Based Surveys of Non-Communicable Diseases: A Conceptual Exploration” *J Med Internet Res* 2017;19(5):e110. DOI: 10.2196/jmir.7326 PMID: 28476723.
 23. Pariyo GW, Wosu AC, Gibson DG, Labrique AB, **Ali J**, Hyder AA “Moving the Agenda on Noncommunicable Diseases: Policy Implications of Mobile Phone Surveys in Low and Middle-Income Countries” *J Med Internet Res* 2017;19(5):e115. DOI: 10.2196/jmir.7302 PMID: 28476720.
 24. Hyder AA, Wosu AC, Gibson DG, Labrique AB, **Ali J**, Pariyo GW
“Noncommunicable Disease Risk Factors and Mobile Phones: A Proposed Research

- Agenda” *J Med Internet Res* 2017;19(5):e133. DOI: 10.2196/jmir.7246 PMID: 28476722.
25. Gibson DG, Pariyo GW, Wosu AC, Greenleaf AR, **Ali J**, Ahmed S, Labrique AB, Islam K, Masanja H, Rutebemberwa E, Hyder AA “Evaluation of Mechanisms to Improve Performance of Mobile Phone Surveys in Low- and Middle-Income Countries: Research Protocol” *JMIR Res Protoc* 2017;6(5):e81. DOI: 10.2196/resprot.7534 PMID: 28476729.
 26. Ralefala D*, **Ali J**, Kass N, Hyder A. “A case study of researchers’ knowledge and opinions about the ethical review process for research in Botswana” *Research Ethics* first published online on November 3, 2016 as doi:10.1177/1747016116677250.
 27. Kass N, **Ali J**, Hallez K, Hyder A. “Bioethics training programmes for Africa: evaluating professional and bioethics-related achievements of African trainees after a decade of Fogarty NIH investment” *BMJ Open* 2016;6:e012758 doi:10.1136/bmjopen-2016-012758 PMCID: PMC5030587
 28. Pratt B, **Ali J**, Hyder A. “If research is a pillar of health system development, why only focus on clinical trials?” *American Journal of Bioethics* Vol. 16, Iss. 6, 2016.
 29. Nwobegahay J*, **Ali J**, Ter Goon D, Hyder A. "Ethical guidelines for military-based health research: an unmet need in Africa?" *South African Journal of Bioethics and Law* [Online], 8.2 (2015): 11-16. Web. 30 Nov. 2015.
 30. **Ali J**, Andrews J, Somkin C, Rabinovich CE. “Harms, Benefits, and the Nature of Interventions in Pragmatic Clinical Trials” *Clinical Trials*, first published online on September 15, 2015 doi:10.1177/1740774515597686.
 31. **Ali J**, Califf R, Sugarman J. “Anticipated Ethics and Regulatory Challenges in PCORnet: The National Patient-Centered Clinical Research Network” *Accountability in Research* 2015 Jul 20. [Epub ahead of print] PubMed PMID: 26192996.
 32. Hyder A, **Ali J**, Hallez K, White T, Sewankambo N, Kass N. “Exploring Institutional Research Ethics Systems: A Case Study from Uganda” *AJOB Empirical Bioethics*. 2015 DOI: 10.1080/23294515.2014.981316.
 33. Kass N, Taylor H, **Ali J**, Hallez K, Chaisson L. “A Pilot Study of Simple Interventions to Improve Informed Consent in Clinical Research: Feasibility, Approach, and Results” *Clinical Trials*. 2015 Feb;12(1):54-66.
 34. Hyder A, Pratt B, **Ali J**, Kass N, Sewankambo N. “The ethics of health systems research in low- and middle-income countries: A call to action” *Global Public Health*. 2014 Aug 7:1-15. DOI:10.1080/17441692.2014.931998.
 35. **Ali J**, Kass N, Sewankambo N, White T, Hyder A. “Evaluating International Research Ethics Capacity Development: An Empirical Approach” *Journal of Empirical Research on Human Research Ethics*, 2014; 9(2), 41-51.
 36. Hyder A, Zafar W, **Ali J**, Ssekubugu R, Ndebele P, Kass N. “Evaluating Institutional Capacity for Research Ethics in Africa: A Case Study from Botswana” *BMC Medical Ethics*. 2013 Jul 30;14:31.
 37. **Ali J**, Hyder A, Kass N. “Research Ethics Capacity Development in Africa: Exploring a Model for Individual Success” *Developing World Bioethics* 2012; 12:2, 55-62.
 38. Taylor HA, Kass NE, **Ali J**, Sisson S, Bertram A, Bhan A. “Development of a Research Ethics Knowledge and Analytical Skills Assessment Tool” *J Med Ethics* 2012;38:236e242. doi:10.1136/medethics-2011-100025.
 39. Aggarwal R, Gupte N, Kass N, Taylor H, **Ali J**, Bhan A, Aggarwal A, Sisson S, Kanchanaraksa S, McKenzie-White J, McGready J, Miotti P, Bollinger R.C. “A

- Comparison of Online versus On-site Training in Health Research Methodology: A Randomized Study” *BMC Medical Education* 2011;11:37.
40. Kaphingst K, **Ali J**, Taylor H, Kass N. “Rapid Estimate of Adult Literacy in Medicine: Feasible by Telephone?” Letter to the Editor. *Family Medicine* 2010;42:7.
 41. **Ali J**. “Global Health Research Ethics – A ten part audio lecture series” *Developing World Bioethics* 2010;10:3, 172–174.
 42. Hyder A, Merritt M, **Ali J**, Tran N, Subramaniam K, Akhtar T. “Integrating ethics, health policy and health systems in low and middle income countries: case studies from Malaysia and Pakistan” *Bulletin of the World Health Organization* 2008;86:606–611.

Books

1. Kahn, J. and the Johns Hopkins Project on Ethics and Governance of Digital Contact Tracing Technologies. Digital Contact Tracing for Pandemic Response: Ethics and Governance Guidance. Baltimore: Johns Hopkins University Press, 2020., [doi:10.1353/book.75831](https://doi.org/10.1353/book.75831). [Co-led research/writing group]

Articles, Editorials and other publications not peer reviewed

1. Book Review: “Health Research Ethics, Safeguarding the Interests of Research Participants” *Journal of Empirical Research on Human Research Ethics* (in press).
2. Agnew M, Katchen M, **Ali J**. “From Principles to Practice Part II: An International Dilemma in Confined Space Entry” *The Synergist*, January 2017.
3. Pratt B, **Ali J**. “How can we Strengthen ‘Ethics’ in Health Systems Research?” Commentary, *Health Systems Global*, October 3, 2016.
4. Agnew M, Katchen M, **Ali J**. “From Principles to Practice: A Framework for International Industrial Hygiene Ethics” *The Synergist*, June/July 2016.

Chapters

1. **Ali J**. “Medical Ethics” In Restivo S, Denton P & Shea E. (eds.), *Battlegrounds: Science and Technology*. Westport, CT: Greenwood Press (2008).
2. **Ali J**. “Medical Marijuana” In Restivo S, Denton P & Shea E. (eds.), *Battlegrounds: Science and Technology*. Westport, CT: Greenwood Press (2008).

Practice-Related Reports

1. African Bioethics Consortium (ABC). “[Research Ethics Committee Assessment Toolkit \(RECAT\)](#)” Johns Hopkins University. Version 1.0. Baltimore Maryland USA, 2017.

2. **Ali J. & Whicher D.** “Ethical and Legal Issues” in Snyder C & Wu A. (eds.), [Users’ Guide to Integrating Patient Reported Outcomes into Electronic Health Records](#), May 2017.
3. **Ali J. & Pratt B.** “Scoping Review on the Ethics of Health Policy & Systems Research” (102pg report). Commissioned by the Alliance for Health Policy & Systems Research/World Health Organization, Geneva Switzerland, June 2015.

PRACTICE ACTIVITIES

Presentations and engagement with policy-makers and others

- New York City Bar Association podcast on Digital Contact Tracing Technologies (in production).
- Organizer/host of a podcast series on [“Ethics, COVID-19 & Africa”](#) with participants from sub-Saharan Africa, Spring/Summer 2020.
- “Ethical Implications of Virtual Humans for Health and Social Support” Robert H. Levi Leadership Symposium and Public Event, under preparation for Fall 2020.
- Workshop participant, “The Nuffield Council’s preliminary approach to ethical issues in research in global health emergencies” Nuffield Council on Bioethics, St. Anne’s College, Oxford University, Oxford, U.K. July 3, 2019.
- “Strengthening the Voice of African Scholars in Global Health Ethics” Hopkins on the Hill event, Capitol Hill, Washington DC, June 12, 2019.
- “Monitoring & Evaluation of Research Ethics Systems” WHO Working Group Meeting on Developing Indicators to Measure the Quality of Research Ethics Oversight, Geneva, Switzerland, May 15, 2019.
- “Research Ethics Committee Assessment Toolkit” Fogarty International Research Ethics Training Program Network Meeting, Fogarty International Center, National Institutes of Health, Bethesda, MD March 22, 2019.
- “Ethics and Regulatory Work Group of the NIH-DoD-VA Pain Management Collaboratory Coordinating Center (PMC³)” PMC Steering Committee Meeting, Bethesda, MD September 17, 2018.
- “Research Ethics Knowledge & Skills Assessment to Support Clinical Trial Development” Tan Tock Seng Hospital (TTSH) Partnership Visit, Johns Hopkins Hospital, Baltimore, MD June 28, 2018.
- User's Guide for Integrating Patient-Reported Outcomes in Electronic Health Records “Ethical & Legal Issues” Patient Reported Outcomes Research Institute (PCORI) Public Dissemination Meeting, Arlington, Virginia May 25-26, 2017.
- “Recommendations to strengthen the University of Zambia Biomedical Research Ethics Committee (UNZABREC)” University of Zambia, Lusaka, Zambia February 22, 2017.
- “Mobile phone surveys for non-communicable disease surveillance in low- and middle-income countries: Exploring the ethical, legal and societal issues” International Technical Workshop – Data for Health Project (host & presenter), Mt. Washington Conference Center, Baltimore, MD November 21-22, 2016.

- “International Research Ethics Training: Program Overview” China GCP Union, Institutional visit to Johns Hopkins University, Baltimore, MD October 6, 2016.
- “International Standards for Ethical Oversight of Clinical Research: Core Principles and IRB Requirements” Clinical Research Workshop & Institutional Dialogue, Johns Hopkins International, Fudan University/Zhongshan Hospital, Shanghai, China April 19-20, 2016.
- “Developing a Tool to Assess Ethics Committee Needs in LMICs” Fogarty International Research Ethics Training Program Network Meeting, Fogarty International Center, National Institutes of Health, Bethesda, MD October 6, 2015.
- “Experiences Advising on Research Ethics Related to Ebola” (Panelist) Fogarty International Research Ethics Training Program Network Meeting, Fogarty International Center, National Institutes of Health, Bethesda, MD October 6, 2015.
- “Scoping Review on the Ethics of Health Policy & Systems Research” (with B. Pratt) Alliance for Health Policy & Systems Research - World Health Organization (WHO) Meeting on Ethics Guidance for Health Policy & Systems Research, University of Zurich, Institute of Biomedical Ethics and History of Medicine, Zurich, Switzerland, July 23, 2015.
- “Lessons Learned about Evaluating Ethics Education Programs” Fogarty International Research Ethics Training Program Network Meeting, Fogarty International Center, National Institutes of Health, Bethesda, MD October 1, 2014.
- “Patient-Centered Portable Consent” (roundtable discussant), Academy Health, Washington D.C. June 24, 2014.
- “Anticipated Ethics & Regulatory Issues in PCORnet – PPRN & CDRN Survey” (with R. Califf & J. Sugarman) Patient Centered Outcomes Research Institute, PCORnet Ethics & Regulatory Task Force April 21 & May 19, 2014.
- “Ethics & Regulatory Task Force Overview” (with R. Califf & J. Sugarman) PCORnet, Patient Centered Outcomes Research Institute, Washington, DC October 11, 2013.
- “Evaluating the Impact of Fogarty African Bioethics Capacity Building Initiatives: A preliminary analysis” (with N. Kass & A. Hyder) Fogarty International Research Ethics Training Program Network Meeting, Fogarty International Center, National Institutes of Health, Bethesda, MD May 2, 2013.
- “Sharing Web Resources - Discussion Panel” Fogarty International Research Ethics Training Program Network Meeting, San Diego, CA December 5, 2010.
- “The Johns Hopkins Berman Institute of Bioethics” International Research Ethics Training Program Network Meeting, NIH Fogarty International Center, Bethesda, MD October 20, 2009.
- “Best Practices in Use of Information Communication Technology (ICT) for Bioethics Training” Fogarty International Research Ethics Training Program Network Meeting, NIH Fogarty International Center, Bethesda, MD October 19, 2009.

Research finding dissemination through media appearances and other communication

venues (federal, state, and local)

OZY, "The fraudulent study that killed thousands of breast cancer patients" (Dec. 2016)

<http://tinyurl.com/gwnq3mt>

Baltimore Sun, "Md. to impose home quarantine, transit limits on some travelers from Ebola-stricken countries" (Oct. 2014). <http://tinyurl.com/knmemwl>

Politico, "Can Big Data and patient-informed consent coexist?" (Sept. 2014).

<http://tinyurl.com/ldk2u9r>

The Rheumatologist Newsmagazine, "ACR/ARHP Annual Meeting 2012: Children Experience Pain Differently from Adults" (March 2013). <http://tinyurl.com/pa8pq93>

B Magazine, Baltimore Sun, "10 People to Watch Under 30" (2011).

<http://tinyurl.com/kxpdp7>

Software development

www.fabtp.com

Website of the *Johns Hopkins Fogarty African Bioethics Training Program*

CURRICULUM VITAE

Joseph Ali

PART II

TEACHING

Advisees/Mentees

Name	Degree	Dates	Title of research, thesis or capstone
Diana Mendoza-Cervantes (University of Pittsburgh School of Medicine)	Dean's Summer Research Program (DSRP)	March 2020 – present	Examining Collective Harms in the Context of Global Health Ethics
Betselot Yirsaw (Addis Ababa University)	Non-degree Fogarty trainee	June 2020	N/A
Olivia Kituuka (Makerere University)	PhD in Bioethics @ Makerere Univ Uganda [JHU mentor]	2020 - present	Informed Consent for Emergency Surgery at Public and Private Hospital Surgical Emergency Units in the Urban Ugandan Setting
Paul Kutyabami (Makerere University)	PhD in Bioethics @ Makerere Univ Uganda [JHU mentor]	2020 - present	Ethics and Data Sharing in Uganda (provisional)
Sylvia Nabukenya (Makerere University)	PhD in Bioethics @ Makerere Univ Uganda [JHU mentor]	2020 - present	Understanding Stakeholder Perspectives, Experiences and Decisional Preferences for the Return of Pharmacogenetics Research Results Among People Living with HIV/AIDS
Norman Carl Swart (University of Botswana)	Post-doc fellow	2019-present	Communication Challenges Experienced by Doctors, Nurses and Patients in the Context of Advanced Cancer Care in Botswana
Choolwe Jacobs (University of Zambia)	Post-doc fellow	2019-present	Exploring Normative Values and Beliefs Influencing Utilisation of Care from Skilled Birth Attendants by Women in a Selected Peri-Urban Area of Zambia
Bakari Sibert (Howard University)	Genomics and Society Mentorship Program	June-Aug 2019	Evaluating Genetics and Genomics Research Ethics Literature for Uganda

Solomon Abay (Addis Ababa University)	Non-degree Fogarty trainee	June 2019	N/A
Yimtubesnash Woldeamanuel (Addis Ababa University)	Non-degree Fogarty trainee	June 2019	N/A
Victor Zulu (University of Zambia)	Post-doc fellow	2018-present	Ethical Issues in Zoonotic Disease Research among Traditional Livestock Keepers: A case study of Zambia
Setlhomu Koloi-Keaikitse (University of Botswana)	Post-doc fellow	2018-present	Cultural Values and Beliefs of Selected Local Communities in Botswana: Implications for Human Subject Research Ethics Practices and Review
Vina Vaswani (Yenepoya University)	Global Forum fellow	2018-19	Developing a White Paper on Ethical Issues in Controlled Human Infection Model (CHIM) Studies in India
Aida Asmelash (Johns Hopkins University)	MBE	2017	Botswana's Duty to Expand Access to Antiretroviral Therapy to Non-Citizen Immigrants
Tara D. White (Johns Hopkins University)	MSPH	2011-13	Evaluation of Research Ethics Capacity Development Programs in sub-Saharan Africa
JHU-Fogarty African Bioethics Trainees (multiple)	Non-degree	2007-2018	Co-mentored approx 30 additional master's-level long-term trainees through funded research studies

Thesis Advisory Committee

Michael DiStefano, PhD Candidate, Bioethics & Health Policy (2019 -)

Preliminary Oral Participation

Michael DiStefano, PhD Candidate, Bioethics & Health Policy (2019)

Formal Courses Taught

- 221.616.81 “Ethics of Public Health Practice in Developing Countries” with Maria Merritt, Johns Hopkins Bloomberg School of Public Health, 4th Term 2020.
- 700.645.01 “Fogarty Bioethics Seminar” Johns Hopkins Bloomberg School of Public Health & Johns Hopkins Berman Institute of Bioethics, Multiple Terms 2009-present.
- 700.665.11 “Introduction to Ethics of U.S. and International Human Subject Research” Johns Hopkins Bloomberg School of Public Health and Johns Hopkins Berman Institute of Bioethics, Summer Institute 2018, 2019.
- 306.665.01 “Research Ethics and Integrity: U.S. and International Issues” Johns Hopkins Bloomberg School of Public Health, Department of Health Policy & Management, 3rd Term 2018.

700.625.01 “Bioethics and the Law” Johns Hopkins Berman Institute of Bioethics, Master of Bioethics (MBE) Program, 1st/3rd Term 2016-2018.
“Practicum Methods Tutorial” Johns Hopkins Fogarty African Bioethics Training Program, Johns Hopkins Berman Institute of Bioethics, 4th Term, 2014-2017.
“Ethics of Human Experimentation” (undergraduate, semester-long) Johns Hopkins University, Krieger School of Arts & Sciences, Department of Philosophy 2013 & 2017.
“The Rhetoric of Pain and Suffering” (with J. Lyne), semester-long graduate course, University of Pittsburgh, Department of Communication, 2006.

Other Significant Teaching

Multiple lectures and interactive sessions under the Johns Hopkins Global Bioethics Training Program - a month-long intensive program offered every June (2013-present).
“Ethical Issues in Multinational Global Health Research” in *Global Bioethics* (Emily Anderson), Loyola University Chicago, July 16, 2020.
“Ethics and Digital Contract Tracing Technologies” in *Digital Health Strategies to Control COVID-19*, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD August 12, 2020.
“Research Ethics” in *Basics of Bioethics*, Johns Hopkins Berman Institute of Bioethics & Bloomberg School of Public Health, Baltimore, MD June 2, 2020.
“Ethics of a Pandemic - Challenges in Control and Care” (with J. Kahn & M. Merritt) in *Current Issues in Public Health: COVID-19 Pandemic Response*, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD April 14, 2020
Ethics Session in *Case Studies in Management Decision-Making*, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD March 4, 2020.
“Global Health Ethics” in *Topics in Interdisciplinary Medicine (TIME)* – *Global Health* course, Johns Hopkins School of Medicine, Baltimore, MD February 24, 2020.
“Current Issues in Human Subjects Research and the Common Rule” in *Seminars in Research Ethics*, MD/PhD Medical Scientist Training Program, Johns Hopkins School of Medicine, Baltimore, MD February 12, 2020.
“Ethics in Public Health Programming” seminar and facilitated discussion, STAR Intern Program, USAID, Washington, D.C. November 8, 2019.
“The Central Role of Values in Global Health: Two cases examples from Uganda” Health Systems Program Seminar, Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD September 17, 2019.
“Applying Common Principles of Research Ethics” University of Malaya, Faculty of Medicine, Master of Health Research Ethics Program Faculty Workshop, Kuala Lumpur, Malaysia August 19, 2019.
“A Framework for Ethical Analysis” University of Malaya, Faculty of Medicine, Master of Health Research Ethics Program Faculty Workshop, Kuala Lumpur, Malaysia August 19, 2019.

- “Fundamentals of Informed Consent” Introduction to American Indian Health Research Ethics Summer Institute, Johns Hopkins Center for American Indian Health, Baltimore, MD July 17, 2019.
- “Introduction to Health Research Ethics” Introduction to American Indian Health Research Ethics Summer Institute, Johns Hopkins Center for American Indian Health, Baltimore, MD July 15, 2019.
- “Research Ethics” in *Basics of Bioethics*, Johns Hopkins Berman Institute of Bioethics & Bloomberg School of Public Health, Baltimore, MD June 6, 2019.
- “Ethics & Chatbots for Mental Health Support and HIV Medication Adherence” *Directed Reading with doctoral student (Brooke Jarrett)*, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD Winter/Spring 2019.
- “Ethics & End-of-Life Care in the Caribbean and Latin America: An exploration of the training landscape” *Independent study with Master’s student (Vivian Altiery De Jesus)*, Johns Hopkins Berman Institute of Bioethics, Baltimore, MD Spring 2019.
- “Legal Methods in Bioethics” in *Methods in Bioethics*, Johns Hopkins Berman Institute of Bioethics & Bloomberg School of Public Health, Baltimore, MD March 6, 2019.
- “Ethics of Health Systems Research: A review of challenges and opportunities” in *Health Systems Research & Evaluation Seminar*, Johns Hopkins Bloomberg School of Public Health, Dept. of International Health, Health Systems Program, Baltimore, MD January 31, 2019.
- “Ethics & Global Digital Health” in *Graduate Doctoral Seminar in Bioethics*, Johns Hopkins Berman Institute of Bioethics & Bloomberg School of Public Health, Baltimore, MD November 5, 2018.
- “Global Bioethics” in *Foundations of Bioethics*, Johns Hopkins Berman Institute of Bioethics & Bloomberg School of Public Health, Baltimore, MD October 17, 2018.
- “Broad Consent for Biobanking in International Health Research” (webinar - moderator), JHU-University of Zambia project to enhance critical infrastructure for HIV/AIDS research June 11, 2018.
- “Ethics and Digital Health in Uganda” Makerere University, College of Health Sciences, Master of Health Research Ethics Program, Kampala, Uganda March 22, 2018.
- “Methods in Bioethics & Law” Makerere University, College of Health Sciences, Master of Health Research Ethics Program, Kampala, Uganda March 22, 2018.
- “Global Bioethics” in *Foundations of Bioethics*, Johns Hopkins Berman Institute of Bioethics & Bloomberg School of Public Health, Baltimore, MD September 14, 2017.
- “Introduction to Health Research Ethics” Introduction to American Indian Health Research Ethics Summer Institute, Johns Hopkins Center for American Indian Health, Baltimore, MD July 10, 2017.
- “Fundamentals of Informed Consent” Introduction to American Indian Health Research Ethics Summer Institute, Johns Hopkins Center for American Indian Health, Baltimore, MD July 12, 2017.

- “Ethics & International Cancer Research” Global Cancer Epidemiology Institute, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD June 26, 2017.
- “Health Systems Research Ethics: Special Issue Webinar” (discussant) May 30, 2017.
- “The goal of valid and respectful informed consent in resource limited countries: data from the field” (webinar moderator), JHU-University of Zambia project to enhance critical infrastructure for HIV/AIDS research February 16, 2017.
- “Legal Methods in Bioethics” in *Methods in Bioethics*, Instructor: Jeremy Sugarman, Johns Hopkins Berman Institute of Bioethics & Bloomberg School of Public Health, Baltimore, MD January 31, 2017.
- “Ethics & Emergency Research” Johns Hopkins – Makerere University Chronic Consequences of Trauma, Injuries and Disability (JHU-MU Chronic-TRIAD) Training Program October 25, 2016.
- “Global Bioethics” in *Foundations of Bioethics*, Johns Hopkins Berman Institute of Bioethics & Bloomberg School of Public Health, Baltimore, MD October 13, 2016.
- “Research Ethics – Principles and Requirements” JHU-Pakistan Fogarty International Collaborative Trauma and Injury Research Training Program, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD July 8, 2016.
- “Ethics & Ethical Review of International Research” Global Cancer Epidemiology Institute, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD June 21, 2016.
- “Ethics & Professionalism in Research,” *Webinar*, Johns Hopkins – Makerere University Chronic Consequences of Trauma, Injuries and Disability (JHU-MU Chronic-TRIAD) Training Program, June 6, 2016.
- “Legal Methods in Bioethics” in *Methods in Bioethics*, Instructor: Matt DeCamp, Johns Hopkins Berman Institute of Bioethics & Bloomberg School of Public Health, Baltimore, MD November 6, 2015.
- “Research ethics in Emergency and Humanitarian Settings” JHU-Pakistan Fogarty International Collaborative Trauma and Injury Research Training Program, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD November 5, 2015.
- “Introduction to International Research Ethics” JHU-Pakistan Fogarty International Collaborative Trauma and Injury Research Training Program, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD November 2, 2015.
- “International Research Ethics,” Johns Hopkins – Makerere University Chronic Consequences of Trauma, Injuries and Disability (JHU-MU Chronic-TRIAD), Johns Hopkins Bloomberg School of Public Health, Baltimore, MD July 14, 2015.
- “Introduction to Health Research Ethics” Introduction to American Indian Health Research Ethics Summer Institute, Johns Hopkins Center for American Indian Health, Baltimore, MD July 13, 2015.
- “Ethics of Research Involving Humans” Global Cancer Epidemiology Institute, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD June 23, 2015.

- “Ethics of Research Involving Prisoners,” HELP Course, Johns Hopkins Berman Institute Bioethics & Bloomberg School of Public Health, Baltimore, MD June 17, 2015.
- “The AZT Debate: Standards and Priorities in HIV Research” in Global Health and Human Rights: Theoretical Foundations and Practical Implications, Instructor: Matthew DeCamp, Johns Hopkins University, Department of Philosophy, Feb 28, 2014.
- “Social Media & Health: Meeting the Ethical Challenges” (with M. DeCamp & D. O’Connor. Role: course organizer & discussion leader) Johns Hopkins Berman Institute Bioethics Intensives, Baltimore, MD January 2013.
- “Ethics & Pain Medicine” (with J. Sugarman) to medical residents and fellows of the Blaustein Pain Treatment Center, Johns Hopkins Outpatient Center, October 10, 2012.
- “Regulation of Research” Johns Hopkins Berman Institute Bioethics Intensives, Baltimore, MD June 15, 2012.
- “Legal Methods in Bioethics” in Methods in Bioethics, Instructor: Jeremy Sugarman, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD February 1, 2011.
- “Research Ethics” Pacific Rim DrPH Program, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD January 2012.
- “Community Engagement” and “Undue Inducement.” JH-FABTP/University of Botswana Research Ethics Workshop, University of Botswana, Gaborone, Botswana October 12-13, 2010.
- “U.S. Research Regulations – IRBs and Informed Consent” and “What Counts as Research.” Ethics in Human Subjects Research in Developing Countries course, Johns Hopkins School of Public Health, Graduate Summer Institute in Epidemiology & Biostatistics, Baltimore, MD June 22-23, 2010.
- “Bioethics” (with J. Sugarman) MHA Program, University of Trinidad and Tobago April-May 2010.
- “Ethics in Human Subjects Research in Developing Countries” (TA) Johns Hopkins Bloomberg School of Public Health and Berman Institute of Bioethics, Summer 2008 & 2010.
- “Introduction to Human Subjects Research” Johns Hopkins ICOHRTA TB & HIV Training Program, Baltimore, MD June 12, 2009.
- World Health Organization (WHO) three-week online research ethics training module, November 2007.
- “Distributive Justice” PhD program in Bioengineering, University of Pittsburgh, Pittsburgh, PA 2005.

RESEARCH GRANT PARTICIPATION

Active

U24AT010961	Sugarman, JHU PI (~\$140,000)	09/28/19 – 06/30/24
Duke University		

HEAL Collaboratory Resource Coordinating Center

This project seeks to operate a coordinating center to support pragmatic studies focused on pain management and opioid use.

Role: Co-I, Ethics & Regulatory Core

R25TW001604-18A1 Ali/Hyder/Addissie (\$1.2M) 04/15/19 – 01/31/24

NIH/Fogarty International

Johns Hopkins University-Addis Ababa University Research Ethics Training Program in Ethiopia (JHU-AAU RETP)

This project builds on 18 years of bioethics capacity strengthening programmatic activity at JHU to create a new track in research ethics within AAU's Master of Public Health program and support research ethics training, scholarship and service in the Ethiopia.

Role: Corresponding PI

1D43TW010892-01A1 Ali (JHU PI) (\$1.2M) 04/15/19 – 01/31/24

NIH/Fogarty International

Makerere University International Bioethics Research Training Program

This project seeks to develop and implement a doctoral program in bioethics at Makerere University in Uganda with components of coursework and mentoring at JHU.

Role: JHU PI

1U24AT009769-01 Kerns (~\$10.2M) 02/01/18 – 08/31/23

NIH/National Center for Complementary & Integrative Health; Office of the Director; National Institute of Neurological Disorders and Stroke

Pain Management Collaboratory Coordinating Center (PMC3)

The Pain Management Collaboratory Coordinating Center (PMC3) seeks to provide national leadership and technical expertise in all aspects of research supporting the design and execution of high impact Demonstration Projects that conduct cost-effective, large-scale, pragmatic clinical trials on nonpharmacological approaches for pain management and other comorbid conditions in veteran or military health care systems, and make data, tools, best practices, and resources from these and other projects available to facilitate research partnerships in VA and DoD health systems.

Role: JHU PI, Co-Chair of PMC3 Ethics and Regulatory Work Group

R25TW010891 Sugarman/Kamarulzaman (\$1.2M) 04/01/18 – 03/31/23

NIH/Fogarty International Center

Developing an International Master's of Research Ethics Program in Malaysia

The goal of the project is to develop and implement a new Master of Research Ethics Studies (MORES) program at the University of Malaya (UM) in Kuala Lumpur, Malaysia. As the first bioethics-related Master's program in Malaysia, MORES will be developed and sustained by leveraging the collective strengths of Johns Hopkins Berman Institute of Bioethics and UM program faculty who are national and international experts in bioethics, medicine, public health, law, science and education.

Role: Co-I, Associate Director

119668 Pariyo (~\$6M) 02/28/15-03/31/23

Bloomberg Philanthropies, USA

Data for Health Initiative

The overall goal of this initiative is to determine the feasibility, quality, validity, and reliability of using mobile phone surveys for non-communicable disease surveillance in low- and middle-income countries.

Role: Lead, ELSI component

1U01HG009822-01A1 Ali (JHU PI) (\$400,000) 07/01/18 – 06/30/22

NIH/ National Human Genome Research Institute

H3Africa: Ethical, Legal and Societal Issues (ELSI) Research Program

Genetics and genomics research in Uganda: Towards context specific ethics guidelines

Through an interdisciplinary collaboration of Ugandan and international experts in bioethics, law, social science, philosophy, genetics and genomics research, and clinical science, this project seeks to undertake a systematic process to document and analyze the ELSI relevant to genetics and genomics research in Uganda and develop GGR ethics guidelines tailored to the Ugandan setting.

Role: JHU PI

D43TW010512 Kass/Hyder/Sewankambo (\$1.2M) 06/01/17 – 05/31/22

NIH/Fogarty International Center

Fogarty African Bioethics Consortium Post-Doctoral Fellowship Program

This project seeks to develop and implement an 18-month bioethics post-doctoral training program for scholars from Zambia, Uganda and Botswana to advance bioethics leadership in sub-Saharan Africa.

Role: Co-I

NIH Bioethics Research Supplement (Milliard) (\$100,000) 09/19 – 08/21 NCE

Supplement to Addis Ababa University HEPI award

Ethical challenges associated with community-based research and training in Ethiopia

Role: JHU Co-PI with Andrea Ruff

G11TW010551 Kass/Hyder/Deressa (\$290,000) 04/26/18 – 03/31/21

NIH/Fogarty International Center

Supporting Performance of the Ethics Committee for Research (SUPER) in Ethiopia

This project aims to strengthen the capacity of the institutional review board (IRB) at the Addis Ababa University, College of Health Sciences in Ethiopia through a series of training, mentoring, and technical assistance activities designed to improve the ethics knowledge of IRB members and the administrative efficiency of IRB operations.

Role: Co-I

G11TW010338 Kass/Hyder/Michelo (\$290,497) 05/06/16-04/30/21 NCE

NIH/Fogarty International Center

Improving the quality and efficiency of the University of Zambia Research Ethics Committee with HIV Research Training

This project works to strengthen the capacity of the research ethics committee (REC) at the University of Zambia School of Medicine through a series of training, mentoring, and technical assistance activities designed to improve the ethics knowledge of REC members and the administrative efficiency of REC operations.

Role: Co-I

Pending

NIH Bioethics Research Supplement to R25TW010891 (Sugarman/Kamarulzaman)

09/20 – 08/21

Role: Co-I

Completed

Greenwall Foundation Taylor/Ford (\$384,479) 07/01/16-06/30/19

Making a Difference in Real-World Bioethics Dilemmas Program

Improving Understanding of Clinical Research Studies: a randomized experimental study to compare two simple informed consent strategies to traditional informed consent in the context of ongoing clinical studies.

Role: Co-Investigator

Clinical Research Pathways Ali (\$15,000) 05/15/18 – 10/30/18

Grant to support travel and living expenses for two short-term trainees' participation in the Johns Hopkins Berman Institute of Bioethics, Global Bioethics Training Program – IRB Practice Track.

Role: Principal Investigator

90068775 Snyder 06/01/16 – 05/31/17

Patient-Centered Outcomes Research Institute

Integrating the Patient's Voice in Electronic Health Records

This project will develop guidance and best practices for collecting patient-reported outcomes and integrating them in electronic health records.

Role: Working group member

3R25TW001604-13S1 Kass/Hyder (\$49,976) 10/01/14 – 01/31/17

NIH/Fogarty International Center

Science Education Partnership Award (Supplement)

Johns Hopkins-Fogarty African Bioethics Training Program

This supplement is to systematically develop and pilot test a comprehensive Institutional Review Board (IRB) needs assessment tool that can be used by IRBs around the world.

Role: Co-Investigator

5R25TW001604-16 (revised) Kass/Hyder (\$88,992) 02/01/15 – 01/31/17

NIH/Fogarty International Center

Science Education Partnership Award (Supplement)

This supplement supports international research ethics training and collaboration with members of Liberia's Research Ethics Committees and the Liberian Ministry of Health and Social Welfare.

Role: Co-Investigator

P122013-499A Sugarman/Califf/Platt (\$255,465) 10/01/13 – 10/31/15

Patient-Centered Outcomes Research Institute (PCORI)

National Patient-Centered Outcomes Research Network (PCORnet)
Coordinating Center – Ethics & Regulatory Task Force (sub-award)
The purpose of this project is to lead the Ethics & Regulatory Task Force for the PCORI National Clinical Research Network Coordinating Center (NCRN CC), in partnership with PCORI and 8 organizations with expertise in developing policies and infrastructure, to support 29 clinical and patient powered research networks as they prepare to conduct national patient-centered comparative effectiveness research.
Role: Co-Lead, Ethics & Regulatory Task Force
Member, IRB Work Group

2015/507854-0 Ali (\$23,742) 03/13/15 – 08/31/15
World Health Organization
Alliance for Health Policy & Systems Research
Scoping Review: Ethics of Health Policy & Systems Research
This project is to conduct a systematic review of ethics issues and guidance relevant to the ethical review of health policy and systems research.
Role: Principal Investigator

3R25TW001604-12S1 Kass (\$50,000) 08/01/11 – 01/31/15
NIH/Fogarty International Center
Science Education Partnership Award (Supplement)
Johns Hopkins-Fogarty African Bioethics Training Program
This supplement is to systematically evaluate the impact of 10 years of NIH/Fogarty-funded bioethics capacity development training activities in Africa.
Role: Co-Investigator

Duke University Weinfurt/Sugarman 07/01/10 – 04/30/13
PREMIS: Preventive Misconception in HIV Prevention Trials
Subaward
The objective of this project is to understand how risk behavior may be related to participants' false beliefs about the prevention trial and the investigational intervention being tested.
Role: Qualitative Interviewer

1RC1RR028876-01 Faden/Kass (\$489,386) 09/30/09 – 08/31/12
National Institutes of Health (NIH) (Challenge Grant)
Research and Treatment in Comparative Effectiveness, QI and IND Research
The major goal of this project is to examine the research-treatment interface in the context of traditional clinical trials, comparative effectiveness research, and quality improvement research. Through the regular interaction of a collaborative expert working group, development of rich case studies, and empirical data collection, this project will develop an original conceptual framework for the research-treatment interface as well as policy recommendations for research oversight and informed consent.
Role: Coordinator

R21AI074005-02S1 Kass (\$131,079) 09/07/10 – 03/31/12
NIH/National Institute of Allergy and Infectious Diseases

Research on Ethical Issues in Human Subjects Research (ARRA Supplement)
Testing Modified Approaches to Informed Consent

The purpose of this supplement is to conduct three additional sub-projects, in-furtherance of a parent R21, that support the goals of creating simplified approaches to informed consent and examining the feasibility of testing them in ongoing clinical trials.

Role: Co-Investigator

R25TW001604-10S1 Kass (\$43,200) 09/01/09 – 2/29/12

NIH/Fogarty International Center

Science Education Partnership Award (ARRA Supplement)

This supplement allows the Johns Hopkins-Fogarty African Bioethics Training Program to develop a collaborative website with both public and private content and interactive workspaces. The site will serve as a platform to integrate the multiple training components of the Johns Hopkins-Fogarty African Bioethics Training Program (FABTP). The site will also serve as a networking and information sharing hub for trainees, alumni, faculty, staff, future partners, and others.

Role: Project Manager

R21 AI074005-01A1 Kass (\$451,000) 04/01/08 – 03/31/11

NIH/National Institute of Allergy and Infectious Diseases

Research on Ethical Issues in Human Subjects Research

Testing Modified Approaches to Informed Consent

The broad goals are to design simple informed consent interventions with an approach relevant to most types of trials; and then determine the feasibility of testing them in the context of 6 ongoing clinical trials at Johns Hopkins.

Role: Coordinator

2 R01 CA087605 Daugherty/Kass 11/15/06 – 04/30/10

University of Chicago (subcontract on grant from National Institutes of Health/National Cancer Institute)

Ethics and Clinical Trials in Advanced Cancer Care

The major goal of this project is to provide qualitative and quantitative analysis of audiotaped discussions between oncologists and cancer patients who are considering enrollment in early phase cancer trials.

Role: Consultant

U01 AI069497 Bollinger (\$1,001,920) 09/22/08 – 12/31/09

NIH/National Institute of Allergy and Infectious Diseases & Fogarty International Center

India OAR Distance Learning Supplement

Byramjee Jeejeebhoy Medical College (BJMC), Pune India: Clinical Trials Unit

The goal of this initiative is to compare, using randomized methods, the outcomes of online vs. on-site training in biostatistics and research ethics among 60 scientists in India. A secondary goal is to systematically develop a research ethics knowledge and analytical skills assessment tool.

Role: Coordinator

ACADEMIC SERVICE

Division and/or Department-level

Member, Steering Committee, Department of International Health, Johns Hopkins Bloomberg School of Public Health (2019-present)
Associate Director, Global Programs, Johns Hopkins Berman Institute of Bioethics (2018-present)
Chair (2019-present), Member (2017-18), Seminar Series Planning Committee, Johns Hopkins Berman Institute of Bioethics
Member, Univ of Maryland/Johns Hopkins Berman Institute health law and bioethics collaborative planning committee (2017-present)
Member, Master of Bioethics (MBE) Admissions Committee, Johns Hopkins Berman Institute of Bioethics and Bloomberg School of Public Health (2015-present)
Member, Academic Programs Development Committee, Johns Hopkins Berman Institute of Bioethics (2010-15)

School-level

Faculty, Research Ethics Workshops about Responsibilities and Duties of Scientists (REWARDS) program, Johns Hopkins School of Medicine (2019-present; quarterly sessions)
Center for AIDS Research (CFAR) K-Club session facilitator, Responsible Conduct of Research (2019)
Faculty Judge, Johns Hopkins Medical Student Research Symposium (2016)
MBE Representative, JHSPH Committee on Academic Standards (2014-15)

University-level

Reviewer, JHU Provost's Undergraduate Research Award (PURA) (2018)

External

External Examiner, Yenepoya University Master's Program in International Research Ethics (M.Sc Research Ethics), Mangalore, India (2018-present)

PRESENTATIONS

Scientific Conferences (selected)

“Clinical Benefits from Incidental Genomic Findings; The Major Factor for Communicating of Results” (part of oral session led by Joseph Ochieng et al) World Congress of Bioethics, Philadelphia, PA June 19-21, 2020. [Conference converted to virtual format due to COVID-19]
“Ethics and Global Digital Health Partnerships” (Symposium organized by J. Ali) World Congress of Bioethics, Philadelphia, PA June 19-21, 2020. [Unable to deliver given late conversion of the conference to a pre-recorded virtual format due to COVID-19 and

- challenges associated with delivering a symposium using the technology required by the conference]
- “Developing an International Master’s of Health Research Ethics (MOHRE) Programme” Chirk Jenn Ng, Sharon Kaur, Joseph Ali & Nisha Gopalan, FERCAP Annual International Conference, Universiti Sains Malaysia, Penang, Malaysia, November 25, 2019.
- “A Randomized Study of Interventions to Improve Consent-Related Understanding and Satisfaction for Clinical Trials” American Society for Bioethics & Humanities (ASBH) 21st Annual Conference, Pittsburgh, PA, October 24, 2019.
- “Distrust Due to Injustice: How Should Health Practitioners Respond?” American Society for Bioethics & Humanities (ASBH) 21st Annual Conference, Pittsburgh, PA, October 26, 2019.
- “Ethics of Global Mobile Phone-Based Noncommunicable Disease Risk Factor Surveillance: Data from the field” and Session Chair (x2), Oxford Global Health and Bioethics International Conference, Keble College, Oxford University, Oxford, U.K. July 1-2, 2019.
- “Lessons from Formative Research: Incentive-Responsiveness, Reliability, and Consent Issues of Mobile Phone Surveys of NCD Risk Factors in LMICs” Information Communication Technology for Development (ICT4D) Conference, Speke Conference Centre, Munyonyo, Uganda April 30, 2019.
- “Biomedical Research Ethics” (session Chair) World Congress of Bioethics, Bangalore, India December 06, 2018.
- “Ethical, Legal and Societal Implication of mHealth for Noncommunicable Disease Surveillance in Resource Limited Countries” World Congress of Bioethics, Bangalore, India December 05, 2018.
- “Examining Cooperation, Completion, and Refusal rates for Mobile Phone Surveys Measuring NCD risk factors in LMICs: a collaboration between researchers and the private sector” (poster) 5th Global Symposium on Health Systems Research, Liverpool, UK October 8-12, 2018.
- “Anticipating the Ethical Challenges of Mobile Phone Surveys for Non-Communicable Disease Surveillance in LMICs: Data from the Field” (poster) Consortium of Universities for Global Health (CUGH) Annual Conference, New York, NY March 16, 2018.
- “Mobile Phone Survey Modalities to Meet Health Information Needs” (panel) Global Digital Health Forum, JW Marriott Hotel, Washington D.C., December 5, 2017.
- “Data from the Field: Ethical, Legal & Policy Challenges of Mobile Phone Surveys” (panel) Global Digital Health Forum, JW Marriott Hotel, Washington D.C., December 4, 2017.
- “The ethics of alternative clinical trial designs and methods in LMIC research,” (invited participant/discussant) Global Forum for Bioethics in Research, Pullman King Power Hotel, Bangkok, Thailand November 28-29, 2017.
- “Mobile phone surveys for global non-communicable disease surveillance: Exploring the ethical challenges” Information Communication Technology for Development (ICT4D) Conference, Hyderabad International Convention Centre, Hyderabad, India May 16, 2017.

- “Mobile Phone Surveys for NCD Risk Factor Surveillance in LMICs” (panel) Global Digital Health Forum, Connected Health Conference Gaylord National Resort & Conference Center, National Harbor, MD December 13-14, 2016.
- “R2HC Grant Development Workshop” (seed funded/sponsored) Johns Hopkins Bloomberg School of Public Health, Baltimore, MD December 2-3, 2016.
- “Ethical and Legal Issues” PRO-EHR Users Guide Work Group Meeting, Arlington, VA July 27, 2016.
- “Ethics Issues in Health Policy & Systems Research (HPSR): Mapping the Literature” 13th International Association of Bioethics (IAB) World Congress of Bioethics, Edinburgh International Conference Centre, Edinburgh, Scotland June 15, 2016.
- “Ethical Review of Research in Botswana: The perspective of researchers” (with Ralefala D. et al) 13th International Association of Bioethics (IAB) World Congress of Bioethics, Edinburgh International Conference Centre, Edinburgh, Scotland June 15, 2016.
- “Best Practices for IRBs – A Benchmarking Exercise” (co-organized & moderated with M. Kasule) University of Botswana, Gaborone, Botswana October 17, 2015.
- “Strategies for Teaching and Learning” (Moderator) JHU Fogarty African Bioethics Training Program Alumni Reunion, Johns Hopkins University, Baltimore, MD December 2, 2014.
- “Evaluating the Impact of Fogarty Programs for Africa” JHU Fogarty African Bioethics Training Program Alumni Reunion, Johns Hopkins University, Baltimore, MD December 1, 2014.
- “Exploring a model for evaluating research ethics capacity development in Africa” (with K. Hallez, N. Kass & A. Hyder) Berman Institute of Bioethics Research Retreat, Baltimore, MD April 10, 2014.
- “Health Systems Research: Do we need a new ethics framework?” Ethics of Health Systems Research in Low- and Middle-Income Countries (Workshop), Johns Hopkins Berman Institute of Bioethics, Baltimore, MD June 13-14, 2013.
- “Enhancing Process of Informed Consent” (Poster) Taylor H, Kass N, Ali J, Chaisson L, Greenhalgh M, Scharfstein D, Sugarman J. PRIM&R Conference, National Harbor, MD December 1-4, 2011.
- “Enhancing Process of Informed Consent” (Poster) Taylor H, Kass N, Ali J, Chaisson L, Greenhalgh M, Scharfstein D, Sugarman J. ASBH Conference, Minneapolis, MN October 13-16, 2011.
- “Comparing Modes of Teaching Research Ethics: In-person v. Online” (with H. Taylor & N. Kass) Berman Institute of Bioethics Research Retreat, St. Paul Conference Center, Baltimore, MD December 16, 2009.
- “De-Voicing Pain: What Science Renders Inarticulate” (with J. Lyne) Panel Presentation. Conference of the Society for Social Studies of Science. Vancouver, Canada. November 4, 2006.

Invited Talks and Seminars

- “Digital Contact Tracing for Pandemic Response: Summary of ethics & governance guidance” Public Health, Surveillance, and Human Rights Network; Social Science Research Council, delivered virtually, July 1, 2020.

- “Digital Technologies and their Ethical Application During the COVID-19 Pandemic” (seminar speaker/panelist) Public Health Emergency Preparedness and Response Ethics Network (PHEPREN) World Health Organization (WHO) and The Global Health Network, delivered virtually, June 1, 2020.
- “Global Digital Health Ethics: A bit More Than Data Protection” Inter-Institute Bioethics Interest Group, U.S. National Institutes of Health (NIH), Bethesda, MD April 2020 [Postponed due to COVID-19]
- “Ethics, Human Rights and Digital Health” Spring Symposium, Center for Public Health and Human Rights, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD May 5, 2020 [Cancelled due to COVID-19].
- “A Global Digital Future for Clinical Ethics Consultation” The 16th Annual International Conference on Clinical Ethics & Consultation (ICCEC) (plenary speaker and session chair) Stellenbosch, South Africa March 31 – April 3, 2020 [Postponed to December 2020 due to COVID-19].
- “Lessons Learned in Developing Master’s-level Training Programs in International Health Research Ethics” (plenary speaker), FERCAP Annual International Conference, Universiti Sains Malaysia, Penang, Malaysia November 25, 2019.
- “Consent for Global Mobile Phone-Based Noncommunicable Disease Risk Factor Surveillance” University of Malaya Faculty of Medicine and Centre for Law and Ethics in Science and Technology (CELEST), Faculty of Laws, Kuala Lumpur, Malaysia August 21, 2019.
- “The Research Ethics Review Process and Challenges at Addis Ababa University and Johns Hopkins University” (panelist) Addis Ababa, Ethiopia May 2, 2019.
- “Emerging Medicolegal Issues for Image-Based and Other Related Clinical Applications of mHealth” Ethical Guidelines for mHealth-based Clinical Support Among Clinicians in Low Resource Settings (workshop) Brocher Foundation, Geneva, Switzerland January 10, 2019.
- “Ethics of Global Digital Health” Yenepoya University, Mangalore, India December 03, 2018.
- “Ethics and Utilization of Digital Health Technology in Humanitarian Contexts” in Ethics in Humanitarian Contexts (panelist), Johns Hopkins Center for Humanitarian Health, Baltimore, MD March 28, 2018.
- “Strategies to Promote Ethical Practices in Research: Potential Risk and Ethical Dilemmas in Digital Research” with Megan Singleton and Stuart C. Ray, Advancing Research in the Digital Age Conference, Johns Hopkins Institute for Clinical and Translational Research, Baltimore, MD February 27, 2018.
- “Ethical, Legal and Societal Challenges of Global Digital Health: What We Know and What We Need to Know to Guide Practice,” Faculty Candidate Seminar, Johns Hopkins Bloomberg School of Public Health & Johns Hopkins Berman Institute of Bioethics, Baltimore, MD February 12, 2018.
- “Ethics Framework for International Industrial Hygiene Practice,” American Industrial Hygiene Conference & Exposition, Baltimore Convention Center, Baltimore, MD May 23, 2016.

- “Harms, Benefit and the Nature of Interventions in Pragmatic Clinical Trials,” Grand Rounds, NIH Collaboratory and PCORnet February 19, 2016.
- “Introductory Remarks” Human Genomics Research Plenary Meeting, University of Botswana with Botswana Ministry of Health, Gaborone, Botswana October 14, 2015.
- “Promoting Research while Respecting Privacy: The Promise and Challenge of using Patient Healthcare Data in Research” (Moderator) 5th International Summit on the Future of Health Privacy, Georgetown University Law Center, Washington, D.C., June 3, 2015.
- “Equipoise, Health Systems Research & Cluster Randomized Trials: A conceptual exploration” Ethics & Health Systems Research in Low- and Middle-Income Countries (Symposium) Brocher Foundation, Geneva, Switzerland Sept 16, 2014.
- “Approaches & Methods for Capacity Building in HPSR: Drawing from the Experiences of FABTP” Health Policy & Systems Research (Group Consultation), Admiral Fell Inn, Baltimore, MD March 10, 2014.
- “Ethics & Pain Research” American College of Rheumatology (ACR/ARHP) Annual Meeting, Washington DC Convention Center November 9, 2012. Reported in The Rheumatologist Newsmagazine – “Children Experience Pain Differently from Adults” March 2013. <http://tinyurl.com/pa8pq93>
- “Roundtable Discussant” TaSkR III Bioethics Workshop, IU - Moi AREP, Indiana University-Purdue University Indianapolis, Indiana April 13, 2011.

ADDITIONAL INFORMATION

Personal statement of research and practice goals, objectives and impact

My scholarly work pursues a range of ethics and regulatory challenges in domestic and global bioethics. Some of my ongoing research includes projects that employ conceptual, qualitative and quantitative methods to study ethical implications of global mobile and digital health, including use of mobile digital technologies to enhance public health surveillance. My research also includes efforts to create and empirically test enhanced approaches to informed consent, for both face-to-face and remote/digital consent; to evaluate the impact of international capacity strengthening initiatives; and to support ethics and regulatory oversight and guideline development for health services/systems research. I’ve served as co-chair of ethics and regulatory work groups for two large pragmatic clinical research networks in the United States: the PCORI National Patient-Centered Outcomes Research Network (PCORnet) and the NIH/VA/DOD Pain Management Collaboratory Coordinating Center. I lead an NIH Fogarty-funded Johns Hopkins University-Addis Ababa University Research Ethics Training Program, and several other ethics capacity strengthening and infrastructure development partnerships that build on a 18 years of collaborative efforts to help strengthen to voice of bioethics research leaders across sub-Saharan Africa. I also serve as associate director of a NIH-funded bioethics training program with the University of Malaya in Kuala Lumpur, Malaysia.

As core faculty and associate director for global programs for the Johns Hopkins Berman Institute of Bioethics, I also engage with colleagues at JHU and other institutions across the Global South to support the development of multidisciplinary research, training and service partnerships in bioethics.

Keywords (for sorting)

global health ethics; digital health ethics; capacity development; research ethics; law & bioethics; public health ethics; pragmatic clinical trials; ethics of health policy & systems research