

*Last updated: 21 March 2017***CURRICULUM VITAE***JOSEPH ALI***PERSONAL DATA**

Business address
Johns Hopkins Berman Institute of Bioethics 1809 Ashland Ave, Deering Hall, Rm 208, Baltimore, MD 21205 Phone: +1-410-614-5370 (office) Fax: +1-410-614-5360 Email: jali@jhu.edu

EDUCATION AND TRAINING

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

Medical or Other Licensure

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

PROFESSIONAL EXPERIENCE

Johns Hopkins Berman Institute of Bioethics	Baltimore, MD
<i>Research Scholar II (Faculty)</i>	2016-present
<i>Research Scholar (Faculty)</i>	2009-2015
Johns Hopkins Bloomberg School of Public Health	Baltimore, MD
Department of International Health	
<i>Associate Faculty</i>	2015-present
Johns Hopkins Berman Institute of Bioethics	Baltimore, MD
& Bloomberg School of Public Health, Dept. of Health Policy & Management	
<i>Senior Administrative Coordinator</i>	2008-09
<i>Administrative Coordinator</i>	2007-08

University of Pittsburgh Center for Bioethics & Health Law (CBHL) <i>Research Assistant for CBHL and Prof. Alan Meisel</i>	Pittsburgh, PA 2005-06
University of Pittsburgh Civil Practice Clinic <i>Certified Legal Intern – Health Law Clinic (represented low-income clients)</i> <i>Health Law Extern – UPMC Shadyside Hospital</i>	Pittsburgh, PA 2005 2004
University of Pittsburgh School of Law <i>Faculty Research Fellow</i>	Pittsburgh, PA 2004-05
Alabama Department of Public Health Office of General Counsel <i>Legal Intern – Attorney General Recruit</i>	Montgomery, AL 2004

PROFESSIONAL ACTIVITIES

Participation on Advisory & Technical Panels

- Member – Working Group –Users’ Guide for Integrating Patient Reported Outcomes into Electronic Health Records (PRO-EHR) (2016-present)
- Member – Stakeholder Panel – Patient-Centered Outcomes Research Oversight Study (2015-present)
- Member – IRB Workgroup – The National Patient-Centered Clinical Research Network (PCORnet), Patient Centered Outcomes Research Institute (PCORI) (2015-present)
- Member – Organizing Committee – NIH Health Care Systems Research Collaboratory, Ethics in Pragmatic Clinical Trials Workshop (2015-16)
- Co-Lead – Ethics & Regulatory Task Force – The National Patient-Centered Clinical Research Network (PCORnet), Patient Centered Outcomes Research Institute (PCORI) (2013-15)
- Member – American Bar Association (ABA) Advisory Panel (2012-14)

Program or Project Development

- Manager – Johns Hopkins-Fogarty African Bioethics Training Program (2007-present)
- Co-creator – African Bioethics Consortium (2012-present)
- Co-creator/Manager – JHU Global Bioethics Training Program (2013-present)
- Co-creator – Master of Bioethics (MBE) Program, JHSPH/Berman Institute (2013-15)
- Co-creator/Manager – Berman Institute Bioethics Intensives Program (2012-15)

Society Membership and Leadership

- Member – International Association of Bioethics (2016-present)
- Member – Health Systems Global (HSG), Ethics Thematic Working Group (2015-present)
- Member – American Bar Association (2008-10)
- Member – Pennsylvania Bar Association (2007-10)

- Member – American Society for Bioethics & Humanities (2003-07)
- 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)

Consultations

- Center for Medical Technology Policy, Baltimore, MD (2009)

EDITORIAL/REVIEW ACTIVITIES

Editorial Board Membership

- Editorial Board Member – Accountability in Research: Policies and Quality Assurance (2015-present)
- 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)

Peer Review Activity

- Accountability in Research: Policies and Quality Assurance
- American Journal of Bioethics: Primary Research
- Annals of Internal Medicine (received “top grade” for reviews conducted, multiple years)
- Bulletin of the World Health Organization
- Developing World Bioethics
- Global Health: Science and Practice
- IRB Ethics & Human Research
- Philosophy, Ethics & Humanities in Medicine
- Pittsburgh Journal of Environmental & Public Health Law
- Trials
- University of Toronto Journal of Bioethics

Ad Hoc Review of Grants, Book Proposals and Journal Special Issues

- The Wellcome Trust Foundation (grant reviewer)
- SAGE Publications
- Rutgers University Press
- Editor – Special issue on global trauma and injury research (2016)

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)

Awards

- Staff Recognition Award – Johns Hopkins Bloomberg School of Public Health (2009)
- Excellence for the Future Award – The Center for Computer-Assisted Legal Instruction (2006)

PUBLICATIONS

Journal Articles – Published/in press, peer reviewed

1. 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* (in press) doi:10.2196/jmir.7326.
2. Pariyo GW, Wosu AC, Gibson DG, Labrique AB, Ali J, Hyder AA "Moving the agenda on non-communicable diseases: policy implications of mobile phone surveys in low and middle-income countries" *J Med Internet Res* (in press) doi:10.2196/jmir.7302
3. Hyder AA, Wosu AC, Gibson DG, Labrique AB, Ali J, Pariyo GW "Non-communicable Disease Risk Factors and Mobile Phones: A Proposed Research Agenda" *J Med Internet Res* (in press) doi:10.2196/jmir.7246.
4. Yakubu A, Hyder A, Ali J, Kass N. "Research Ethics Committees in Nigeria: A survey of operations, functions and needs" *IRB: Ethics & Human Research* (in press).
5. 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* (in press).
6. 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
7. 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.
8. 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 PMID: PMC5030587
9. 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.
10. 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.

11. 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.
12. 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.
13. 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.
14. 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.
15. 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.
16. 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.
17. 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.
18. 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.
19. 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.
20. 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.
21. 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.
22. Ali J. "Global Health Research Ethics – A ten part audio lecture series" Review. *Developing World Bioethics* 2010;10:3, 172–174.
23. 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 and Book 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).

Reports, Manuals and Technical Guidelines

1. Ali J. & Whicher D. "Ethical and Legal Issues" in Snyder C & Wu A. (eds.), Integrating Patient Reported Outcomes into Electronic Health Records: A User Guide (forthcoming).
2. 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 of the World Health Organization (WHO), June 2015.

Journal Articles, Editorials and Commentaries – Not peer reviewed

1. Agnew M, Katchen M, Ali J. "From Principles to Practice Part II: An International Dilemma in Confined Space Entry" *The Synergist* January 2017.
2. Pratt B, Ali J. "How can we Strengthen 'Ethics' in Health Systems Research?" Commentary, *Health Systems Global*, October 3, 2016.
3. Agnew M, Katchen M, Ali J. "From Principles to Practice: A Framework for International Industrial Hygiene Ethics" *The Synergist* June/July 2016.

Manuscripts Under Review/Development (selected)

1. *Gibson DG, *Pariyo GW, Wosu AC, Greenleaf AR, Ali J, Ahmed S, Labrique AB, Hyder AA "A protocol for evaluating the effect of incentives and survey delivery modalities on mobile phone survey metrics" *J Med Internet Res* (under review)
2. Deutsch-Feldman M, Ali J, Kass N, Phaladze N, Michelo C, Sewankambo N, Hyder A, "Improving institutional research ethics capacity assessments: lessons from three case studies in sub-Saharan Africa" (under development)

PRACTICE ACTIVITIES**Presentations to policy-makers and other stakeholders**

- "Review of 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" Technical Workshop – Data for Health Project (host & presenter), Mt. Washington Conference Center, Baltimore, MD November 21-22.
- "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.

Media appearances

- 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/kxpxpd7>

Software/website development

- www.fabtp.com

CURRICULUM VITAE – PART II

JOSEPH ALI

TEACHING

Advisees

Name	Degree	Dates	Title of doctoral thesis, MSPH essay or MPH capstone
Tara D. White	MSPH	2011-13	Evaluation of Research Ethics Capacity Development Programs in sub-Saharan Africa
JHU-Fogarty African Bioethics Trainees	Non-degree	2007-present	Supported/advised approx. 30 individual trainee practicum research projects

Classroom Instruction

- “Ethics of Human Experimentation” (undergraduate, semester-long) Johns Hopkins University, Krieger School of Arts & Sciences, Department of Philosophy 2013 & 2017.
- “Law & Bioethics” (with A. Siegel) Johns Hopkins Berman Institute of Bioethics, Master of Bioethics (MBE) Program, 2016-present.
- “Fogarty Bioethics Seminar” (with N. Kass & A. Hyder) Johns Hopkins Bloomberg School of Public Health & Johns Hopkins Berman Institute of Bioethics, 3rd/4th Term 2009-present.
- “Practicum Methods Tutorial” Johns Hopkins Fogarty African Bioethics Training Program, Johns Hopkins Berman Institute of Bioethics, 4th Term, 2014-present.
- “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.
- “Research Ethics” Pacific Rim DrPH Program, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD January 2012.
- “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.
- World Health Organization (WHO) three-week online research ethics training module, November 2007.
- “The Rhetoric of Pain and Suffering” (with J. Lyne), semester-long graduate course, University of Pittsburgh, Department of Communication, 2006.

Other Significant Teaching

- “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, Instructor: Jeffrey Kahn, 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,” Johns Hopkins Berman Institute Bioethics Intensives, 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.
- “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.
- “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.
- “Introduction to Human Subjects Research” Johns Hopkins ICOHRTA TB & HIV Training Program, Baltimore, MD June 12, 2009.
- “Distributive Justice” PhD program in Bioengineering, University of Pittsburgh, Pittsburgh, PA 2005.

RESEARCH GRANT PARTICIPATION

Active

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

Greenwall Foundation Kass/Ford (\$384,479) 07/01/16-06/30/18

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

G11TW010338 Kass/Hyder/Michelo (\$290,497) 05/06/16-04/30/19

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-Investigator

119668 Hyder (\$1,500,000) 02/28/15-03/01/17

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: Co-Investigator

R25 TW001604-16 Kass/Hyder (\$1,250,000) 10/01/00 – 01/31/18 (NCE)

NIH/Fogarty International Center

Science Education Partnership Award

Johns Hopkins-Fogarty African Bioethics Training Program

The Johns Hopkins-Fogarty African Bioethics Training Program (FABTP) is the coordinating center for the African Bioethics Consortium, a network devoted to international research ethics training and enhancing bioethics capacities, resources, structures and strategies within African institutions. Consortium member-institutions currently include the Makerere University, College of Health Sciences (Uganda); the University of Botswana, Office of Research and Development; the University of Zambia, School of Medicine; and the Johns Hopkins Berman Institute of Bioethics and Bloomberg School of Public Health.

Role: Co-Investigator & Manager

5R25TW001604-16 (revised) Kass/Hyder (\$88,992) 02/01/15 – 01/31/18 (NCE)
 NIH/Fogarty International Center
 Science Education Partnership Award (Supplement)
 Johns Hopkins-Fogarty African Bioethics Training Program
 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

3R25TW001604-13S1 Kass/Hyder (\$49,976) 10/01/14 – 01/31/18 (NCE)
 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

Completed

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

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

Department/Unit

- Member, Master of Bioethics (MBE) Admissions Committee, Berman Institute of Bioethics (2015-Present)
- Member, Academic Programs Development Committee, Berman Institute of Bioethics (2010-15)

School/University

- Faculty Judge, Johns Hopkins Medical Student Research Symposium (2016)
- MBE Representative, JHSPH Committee on Academic Standards (2014-15)

PRESENTATIONS

Meetings & Conferences

- “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) 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.
- “Ethics Framework for International Industrial Hygiene Practice,” American Industrial Hygiene Conference & Exposition, Baltimore Convention Center, Baltimore, MD May 23, 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

- “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 research objectives

My work focuses on capacity strengthening and research in the areas of global bioethics and research ethics. I am involved in several ongoing efforts to support training and collaborative partnerships in research ethics internationally, particularly across sub-Saharan Africa. My

research in this area has focused primarily on establishing descriptive and evaluative measures of global capacity strengthening initiatives. With colleagues, I developed frameworks and instruments for assessing training program design and impact at individual, institutional and national levels to support empirically-oriented capacity strengthening. This work aims to document the impact of capacity strengthening programs and collaborations, and identify strategies to help ensure the alignment of programmatic activities with essential needs.

My conceptual and empirical work also includes identifying and assessing emerging ethical issues in international health systems research and m/eHealth, the creation and evaluation of interventions to improve informed consent for clinical research, and the systematic development of a research ethics knowledge and skills assessment tool, and among other projects. This work has been supported by the US NIH, WHO, Bloomberg Philanthropies, Brocher Foundation, and UK Wellcome Trust.

Additionally, in my role as Co-Lead of the National Patient-Centered Clinical Research Network (PCORnet) Ethics & Regulatory Task Force (www.pcornet.org), I contributed to the design and development of infrastructure to support a large national (US) effort to advance evidence-based medicine and patient-centered comparative effectiveness research. As part of these efforts I contributed to the coordination of Institutional Review Board (IRB) review for multi-site research, the identification of emerging ethics and regulatory issues in patient-centered outcomes research, and the ethical assessment of net risk in pragmatic clinical trials.

Keywords

- bioethics
- research ethics/oversight
- public health ethics
- global capacity development
- patient-centered outcomes research
- pragmatic clinical trials
- health policy & systems research
- legal/policy analysis