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Education

School, City, State	Degree, Major	Year
Iowa State University, Ames, IA	B.S., Nutrition	1985
Boston University, Boston, MA	M.P.H., Health Law concentration	1995
University of North Carolina, Chapel Hill, NC	Ph.D., Health Policy (Epidemiology minor)	2005

- *Dissertation title: "Recruiting Research Participants through Cancer Registries: Stakeholder Perspectives" (Chair: Morris Weinberger, PhD, Distinguished Professor)*

Employment and Academic Appointments

Institution	Position/Title	Dates
Post-MPH:		
Stanford University, Center for Biomedical Ethics, Palo Alto, CA	Associate Director & Coordinator, Program in Genomics, Ethics & Society	1996 – 1998
Centers for Disease Control & Prevention, Office of Genetics & Disease Prevention, Atlanta, GA	Career Development Awardee, Association of Teachers of Preventive Medicine	1999 – 2001
Post-PhD:		
Duke Institute for Genome Sciences & Policy, Center for Genome Ethics, Law & Policy, Durham, NC	Senior Research Scholar	2006
Duke Institute for Genome Sciences & Policy, Center for Genome Ethics, Law & Policy, Durham, NC	Assistant Research Professor	2007 – 2013

Duke Clinical Research Institute and Duke University School of Medicine, Durham, NC	Associate Professor of Medicine (Research)	2013 – 2016
Duke Clinical Research Institute and Duke University School of Medicine, Durham, NC	Professor in Medicine (Research)	2016 – 2017
Department of Health Policy, Vanderbilt University School of Medicine, Nashville, TN	Professor of Health Policy	2017 – present
Vanderbilt University Medical Center, Nashville, TN	Ann Geddes Stahlman Chair in Medical Ethics	2018 – present

Publications

Refereed journals:

1. Koenig BA, Greely HT, **McConnell LM**, Silverberg HL, Raffin TA. Genetic testing for BRCA1 and BRCA2: recommendations of the Stanford Program in Genomics, Ethics, and Society. *Journal of Women's Health* 1998; 7(5): 531-45.

2. **McConnell LM**, Koenig BA, Greely HT, Raffin TA. Genetic testing and Alzheimer disease: has the time come? *Nature Medicine* 1998; 4(7): 757-9.

3. **McConnell LM**, Goldstein MK. The application of medical decision analysis to genetic testing: an introduction. *Genetic Testing* 1999; 3(1): 65-70.

4. **McConnell LM**, Sanders G, Owens DK. Evaluation of genetic tests: APOE genotyping for the diagnosis of Alzheimer disease. *Genetic Testing* 1999; 3(1): 47-53.

5. Tobin SL, Chun N, Powell TM, **McConnell LM**. The genetics of Alzheimer disease and the application of molecular tests. *Genetic Testing* 1999; 3(1): 37-45.

6. **McConnell LM**. Understanding genetic testing for Alzheimer disease: medical and epidemiological background. *Genetic Testing* 1999; 3(1): 21-7.

7. **McConnell LM**, Koenig BA, Greely HT, Raffin TA. Genetic testing and Alzheimer disease: recommendations of the Stanford Program in Genomics, Ethics, and Society. *Genetic Testing* 1999; 3(1): 3-12.

8. **Beskow LM**, Khoury MJ, Baker TG, Thrasher JF. The integration of genomics into public health research, policy, and practice. *Community Genetics* 2001; 4(1): 2-11.

9. **Beskow LM**, Burke W, Merz JF, Barr PA, Terry S, Penchaszadeh VB, Gostin LO, Gwinn M, Khoury MJ. Informed consent for population-based research involving genetics. *JAMA* 2001; 286(18): 2315-21.

10. **Beskow LM**, Botkin JR, Daly M, Juengst ET, Lehmann LS, Merz JF, Pentz R, Press NA, Ross LF, Sugarman J, Susswein LR, Terry SF, Austin MA, Burke W. Ethical issues in identifying and recruiting participants for familial genetic research. *American Journal of Medical Genetics* 2004; 130A: 424-31.

11. **Beskow LM**, Sandler RS, Millikan RC, Weinberger M. Patient perspectives on research recruitment through cancer registries. *Cancer Causes & Control* 2005; 16(10): 1171-5.

12. Stitzenberg KB, Thomas NE, **Beskow LM**, Ollila DW. Population-based analysis of lymphatic mapping and sentinel lymphadenectomy utilization for intermediate thickness melanoma. *Journal of Surgical Oncology* 2006; 93(2): 100-7.

13. **Beskow LM**, Millikan RC, Sandler RS, Godley PA, Weiner BJ, Weinberger M. The effect of physician permission versus notification on research recruitment through cancer registries. *Cancer Causes & Control* 2006; 17(3): 315-23.

14. **Beskow LM**, Sandler RS, Weinberger M. Research recruitment through U.S. central cancer registries: balancing privacy and scientific issues. *American Journal of Public Health* 2006; 96(11): 1920-6 [PMC1751818].

15. Bailey DB Jr, **Beskow LM**, Davis AM, Skinner D. Changing perspectives on the benefits of newborn screening. *Mental Retardation and Developmental Disabilities Research Reviews* 2006; 12(4): 270-9.

16. Carpenter WR, **Beskow LM**, Blocker DE, Forlenza MJ, Kim AE, Pevzner ES, Rose JM, Tran AN, Webber KH, Knight K, O'Malley MS. Towards a more comprehensive understanding of cancer burden in North Carolina: Priorities for intervention. *North Carolina Medical Journal* 2008; 69(4): 275-82 [PMC2743945].

17. Glickman SW, Anstrom KJ, Lin L, Chandra A, Laskowitz DT, Woods CW, Freeman DH, Kraft M, **Beskow LM**, Weinfurt KP, Schulman KA, Cairns CB. Challenges in enrollment of minority, pediatric, and geriatric patients in emergency and acute care clinical research. *Annals of Emergency Medicine* 2008; 51(6): 775-80.

18. Haga SG, **Beskow LM**. Ethical, legal, and social implications of biobanks for genetics research. *Advances in Genetics* 2008; 60: 505-44.

19. **Beskow LM**, Dean E. Informed consent for biorepositories: assessing prospective participants' understanding and opinions. *Cancer Epidemiology, Biomarkers & Prevention* 2008; 17(6): 1440-51.

20. **Beskow LM**, Dame L, Costello EJ. Certificates of Confidentiality and compelled disclosure of data. *Science* 2008; 322(5904): 1054-5 [PMC2694567].

21. **Beskow LM**, Smolek SJ. Prospective biorepository participants' perspectives on access to research results. *Journal of Empirical Research on Human Research Ethics* 2009; 4(3): 99-111 [PMC2892166].

22. **Beskow LM**, Grady C, Iltis AS, Sadler JZ, Wilfond BS. Points to consider: the relationship between research ethics consultation and institutional review boards. *IRB: Ethics & Human Research* 2009; 31(6): 1-9 [PMC2921073].

23. **Beskow LM**, Linney KN, Radtke RA, Heinzen EL, Goldstein DB. Ethical challenges in genotype-driven research recruitment. *Genome Research* 2010; 20(6): 705-9 [PMC2877567].

24. **Beskow LM**, Burke W. Offering individual genetic research results: context matters. *Science Translational Medicine* 2010; 2(38): 38cm20 [PMC3136874].

25. McGuire AL, **Beskow LM**. Informed consent in genomics and genetic research. *Annual Review of Genomics and Human Genetics* 2010; 11: 361-81 [PMC3216676].

26. **Beskow LM**, Friedman J, Hardy C, Lin L, Weinfurt KP. Simplifying informed consent for biorepositories: stakeholder perspectives. *Genetics in Medicine* 2010; 12(9): 567-72 [PMC3250643].

27. Clayton EW, Smith M, Fullerton SM, Burke W, McCarty CA, Koenig BA, McGuire AL, **Beskow LM**, Dressler L, Lemke AA, Ramos EM, Rodriguez LL. Confronting real time ethical, legal, and social issues in the eMERGE (Electronic Medical Records and Genomics) Consortium. *Genetics in Medicine* 2010; 12(10): 616-20 [PMC3090678].

28. **Beskow LM**, Friedman J, Hardy C, Lin L, Weinfurt KP. Developing a simplified consent form for biobanking. *PLoS One* 2010; 5(10): e13302 [PMC2951917].

29. Fabsitz RR, McGuire AL, Sharp RR, Hudson K, Pandey M, **Beskow LM**, Biesecker LG, Bookman E, Burke W, Burchard EG, Church G, Clayton EW, Eckfeldt J, Fernandez C, Fisher R, Fullerton SM, Gabriel S, James C, Jarvik GP, Kittles R, Leib J, O'Donnell C, O'Rourke PP, Rodriguez LL, Romero F, Schully SD, Shuldiner AR, Sze RKF, Thakuria J, Wolf SM, Burke GL. Ethical and practical guidelines for reporting genetic research results to study participants: updated guidelines from an NHLBI Working Group. *Circulation: Cardiovascular Genetics* 2010; 3(6): 574-80 [PMC3090664].

30. Tabor HK, Brazg T, Crouch J, Namey EE, Fullerton SM, **Beskow LM**, Wilfond BS. Parent perspectives on pediatric genetic research and the implications for genotype-driven research recruitment. *Journal of Empirical Research on Human Research Ethics* 2011; 6(4): 41-52 [PMC3426316].

31. Cadigan RJ, Michie M, Henderson GE, Davis AM, **Beskow LM**. The meaning of genetic research results: reflections from individuals with and without a known genetic disorder. *Journal of Empirical Research on Human Research Ethics* 2011; 6(4): 30-40 [PMC3386306].

32. Namey EE, **Beskow LM**. Epilepsy patient-participants and genetic research results as 'answers.' *Journal of Empirical Research on Human Research Ethics* 2011; 6(4): 21-9 [PMC3399113].

33. **Beskow LM**, Namey EE, Cadigan RJ, Brazg T, Crouch J, Henderson GE, Michie M, Nelson DK, Tabor HK, Wilfond BS. Research participants' perspectives on genotype-driven research recruitment. *Journal of Empirical Research on Human Research Ethics* 2011; 6(4): 3-20 [PMC3395316].

34. **Beskow LM**, Burke W, Fullerton SM, Sharp RR. Offering aggregate results to participants in genomic research: benefits and challenges. *Genetics in Medicine* 2012; 14(4): 490-6 [PMC3612423].

35. Wolf SM, Crock BN, Van Ness B, Lawrenz F, Kahn JP, **Beskow LM**, Cho MK, Christman MF, Green RC, Hall R, Illes J, Keane M, Knoppers BM, Koenig BA, Kohane IS, LeRoy B, Maschke KJ, McGeveran W, Ossorio P, Parker LS, Petersen GM, Richardson HS, Scott JA, Terry SF, Wilfond BS, Wolf WA. Managing incidental findings and research results in genomic research involving biobanks and archived datasets. *Genetics in Medicine* 2012; 14(4): 361-84 [PMC3597341].

36. **Beskow LM**, Namey EE, Miller PR, Nelson DK, Cooper A. IRB chairs' perspectives on genotype-driven research recruitment. *IRB: Ethics & Human Research* 2012; 34(3): 1-10 [PMC3632007].

37. **Beskow LM**, Fullerton SM, Namey EE, Nelson DK, Davis AM, Wilfond BS. Recommendations for ethical approaches to genotype-driven research recruitment. *Human Genetics* 2012; 131(9): 1423-31 [PMC3686635].

38. Michie M, Cadigan RJ, Henderson G, **Beskow LM**. Am I a control? Genotype-driven research recruitment and self-understandings of study participants. *Genetics in Medicine* 2012; 14(12): 983-9 [PMC3578310].

39. **Beskow LM**, Check DK, Namey EE, Dame LA, Lin L, Cooper A, Weinfurt KP, Wolf LE. Institutional review boards' use and understanding of Certificates of Confidentiality. *PLoS One* 2012; 7(9): e44050 [PMC3433491].

40. Wolf LE, Dame LA, Patel M, Williams B, Austin J, **Beskow LM**. Certificates of Confidentiality: Legal counsels' experiences with and perspectives on legal demands for research data. *Journal of Empirical Research on Human Research Ethics* 2012; 7(4): 1-9 [PMC3640418].

41. DuBois JM, **Beskow LM**, Campbell J, Dugosh K, Festinger D, Hartz S, James R, Lidz C. Restoring balance: the protection of "vulnerable" research participants. *American Journal of Public Health* 2012; 102(12): 2220-5 [PMC3493853].

42. Peppercorn J, Hamilton E, Marcom PK, **Beskow LM**, Lyman GH. Pharmacogenetic testing in the face of unclear clinical efficacy: Lessons from cytochrome P450 2D6 for tamoxifen. *Cancer* 2013; 119(20): 3703-9.

43. Check DK, Wolf LE, Dame LA, **Beskow LM**. Certificates of confidentiality and informed consent: perspectives of IRB chairs and institutional legal counsel. *IRB: Ethics & Human Research* 2014; 36(1): 1-8 [PMC4076050].

44. Botkin JR, Anderson R, Murray T, **Beskow LM**, Kelleher K, Maschke K, Cuttler L. Proposed regulations for research with biospecimens: responses from stakeholders at CTSA consortium institutions. *American Journal of Medical Genetics* 2014; 164A(4): 892-7 [PMC3960336].

45. **Beskow LM**, Check DK, Ammarell N. Research participants' understanding of and reactions to Certificates of Confidentiality. *AJOB Empirical Bioethics* 2014; 5(1): 12-22 [PMC3927918].

46. **Beskow LM**, Dombeck C, Thompson C, Watson-Ormond K, Weinfurt KP. Informed consent for biobanking: consensus-based guidelines for adequate comprehension. *Genetics in Medicine* 2015; 17(3): 226-33 [PMC4336635].

47. McKinney R, **Beskow LM**, Ford D, Lantos J, McCall J, Patrick-Lake B, Pletcher M, Rath B, Schmidt H, Weinfurt KP. Use of altered consent in pragmatic clinical research. *Clinical Trials* 2015; 12(5): 494-502 [PMC4688909].

48. NIH Health Care Systems Research Collaboratory Cluster Randomized Trial Workshop. Ethical and regulatory issues of pragmatic cluster randomized trials in contemporary health systems. *Clinical Trials* 2015; 12: 276-86 [PMC4498459].

49. Wolf SM, Branum R, Koenig BA, Petersen GM, Berry SA, **Beskow LM**, Daly MB, Fernandez CV, Green RC, LeRoy BS, Lindor N, O'Rourke PP, Radecki Breitkopf C, Rothstein MA, Van Ness B, Wilfond BS. Returning a research participant's genetic results to relatives: analysis and recommendations. *Journal of Law, Medicine & Ethics* 2015; 43(3): 440-63 [PMC4617203].

50. **Beskow LM**, O'Rourke PP. Return of genetic research results to participants and families: IRB perspectives and roles. *Journal of Law, Medicine & Ethics* 2015; 43(3): 502-13 [PMC4617597].

51. Fernandez CV, O'Rourke PP, **Beskow LM**. Canadian Research Ethics Board leadership attitudes to the return of genetic research results to individuals and their families. *Journal of Law, Medicine & Ethics* 2015; 43(3): 514-22 [PMC4617195].

52. Wolf LE, Patel MJ, Williams BA, Austin JL, Dame LA, **Beskow LM**. Certificates of Confidentiality: Protecting human subject research data in law and practice; *Journal of Law, Medicine & Ethics* 2015; 43(3): 594-609 [PMC4636332].

53. **Beskow LM**. Lessons from HeLa cells: The ethics and policy of biospecimens. *Annual Review of Genomics and Human Genetics* 2016; 17: 395-417 [PMC5072843].

54. Weinfurt KP, Bollinger JM, Brelsford KM, Crayton TJ, Topazian RJ, Kass NE, **Beskow LM**, Sugarman J. Patients' views concerning research on medical practices: Implications for consent. *AJOB Empirical Bioethics* 2016; 7(2): 76-91 [PMC5085261].

55. **Beskow LM**, Lin L, Dombeck CB, Gao E, Weinfurt KP. Improving biobank consent comprehension: A national randomized survey to assess the effect of a simplified form and review/retest intervention. *Genetics in Medicine* 2017; 19(5): 505-12 [PMC5391302].

56. Obeid JS, **Beskow LM**, Rape M, Gouripeddi R, Black RA, Cimino JJ, Embi PJ, Weng C, Marnocha R, Buse JB for the CTSA Methods and Process and Informatics Domain Task Force Workgroup. A survey of practices for the use of electronic health records to support research recruitment. *Journal of Clinical and Translational Science* 2017; 1(4): 246-52 [PMC5890320].

57. Burke W, **Beskow LM**, Trinidad SB, Fullerton SM, Brelsford KM. Informed consent in translational genomics: insufficient without trustworthy governance. *Journal of Law, Medicine & Ethics* 2018; 46(1): 79-86 [PMC6023399].

58. Wolf SM, Scholtes E, Koenig BA, Petersen GM, Berry SA, **Beskow LM**, Daly MB, Fernandez CV, Green RC, LeRoy BS, Lindor NM, O'Rourke PP, Radecki Breitkopf C, Rothstein MA, Van Ness B, Wilfond BS. Pragmatic tools for sharing genomic research results with the relatives of living and deceased research participants. *Journal of Law, Medicine & Ethics* 2018; 46(1): 87-109 [PMC6040667].

59. Brelsford KM, Spratt SE, **Beskow LM**. Research use of electronic health records: patients' perspectives on contact by researchers. *Journal of the American Medical Informatics Association* 2018; 25(9): 1122–29 [PMC6118867].

60. Wolf LE, **Beskow LM**. New and improved? 21st Century Cures Act revisions to Certificates of Confidentiality. *American Journal of Law & Medicine* 2018;44(2-3): 343-58 [PMC6173954].

61. Brelsford KM, Ruiz E, **Beskow LM**. Developing informed consent materials for non-English speaking participants: an analysis of four professional firm translations from English to Spanish. *Clinical Trials* 2018; 15(6): 557-66 [PMC6218315].

62. **Beskow LM**, Hammack CM, Brelsford KM. Thought leader perspectives on benefits and harms in precision medicine research. *PLoS One* 2018; 13(11): e0207842 [PMC6258115].

63. Hammack CM, Brelsford KM, **Beskow LM**. Thought leader perspectives on participant protections in precision medicine research. *Journal of Law, Medicine & Ethics* 2019; 47(1): 134-48 [PMC6515916].

64. **Beskow LM**, Brelsford KM, Hammack CM. Patient perspectives on use of electronic health records for research recruitment. *BMC Medical Research Methodology* 2019; 19(1): 42 [PMC6390331].

65. **Beskow LM**, Weinfurt KP. Exploring understanding of "understanding": The paradigm case of biobank consent comprehension. *American Journal of Bioethics* 2019; 19(5): 6-18 [PMC6824537].

66. Wolf LE, **Beskow LM**. Genomic databases, subpoenas, and Certificates of Confidentiality. *Genetics in Medicine* 2019; 21(12): 2681-2 [PMC6892737].

67. Brelsford KM, Ruiz E, Hammack CM, **Beskow LM**. Improving translation and cultural appropriateness of Spanish-language consent materials for biobanks. *Ethics & Human Research* 2019; 41(5): 16-27 [PMC6856797].

68. Shinall MC, Hoskins A, Hawkins AT, Bailey C, Brown A, Agarwal R, Duggan MC, **Beskow LM**, Periyakoil VS, Penson DF, Jarrett RT, Chandrasekhar R, Ely EW. A randomized trial of a specialist palliative care intervention for patients undergoing surgery for cancer: rationale and design of the Surgery for Cancer with Option of Palliative Care Expert (SCOPE) Trial. *Trials* 2019; 20(1): 713 [PMC6907134].

69. Rothstein MA, Zawati MH, **Beskow LM**, Brelsford KM, Brothers KB, Hammack-Aviran CM, Hazel JW, Joly Y, Lang M, Patrinos D, Saltzman A, Knoppers BM. Legal and ethical challenges of international direct-to-participant genomic research: Conclusions and recommendations. *Journal of Law, Medicine & Ethics* 2019; 47(4): 705-31 [PMC ID in process].

70. Hammack-Aviran CM, Brelsford KM, **Beskow LM**. Ethical considerations in the conduct of unregulated mHealth research: expert perspectives. *Journal of Law, Medicine & Ethics* 2020; 48(1_suppl): 9-20 [PMC ID in process].

71. **Beskow LM**, Hammack-Aviran CM, Brelsford KM, O'Rourke PP. Expert perspectives on oversight for unregulated mHealth research: empirical data and commentary. *Journal of Law, Medicine & Ethics* 2020; 48(1_suppl): 138-46 [PMC ID in process].

72. Rothstein MA, Wilbanks JT, **Beskow LM**, Brelsford KM, Brothers KB, Doerr M, Hammack-Aviran CM, McGowen ML, Tovino SA. Unregulated health research using mobile devices: ethical considerations and policy recommendations. *Journal of Law, Medicine & Ethics* 2020; 48(1_suppl): 196-226 [PMC ID in process].

73. Wolf LE, Hammack-Aviran CM, Brown EF, Brelsford KM, **Beskow LM**. Protecting participants in genomic research: understanding the "web of protections" afforded by federal and state law. *Journal of Law, Medicine & Ethics* 2020; 48(1): 126-41 [PMC ID in process].

74. Hammack-Aviran CM, Brelsford KM, McKenna KC, Graham RD, Lampron ZM, **Beskow LM**. Research use of electronic health records: patients' views on alternative approaches to permission. *AJOB Empirical Bioethics* 2020 Apr 27 [Epub ahead of print]; doi: 10.1080/23294515.2020.1755383.

75. **Beskow LM**, Hammack-Aviran CM, Brelsford KM. Developing model biobanking consent language: What matters to prospective participants? *BMC Medical Research Methodology* 2020; 20(1):119 [PMC ID in process].

76. **Beskow LM**, Hammack-Aviran CM, Brelsford KM. Thought leader comparisons of risks in precision medicine research. *Ethics & Human Research*; in press.

77. Project Baseline Health Study Group. The Project Baseline Health Study: a step towards a broader mission to map human health. *npj Digital Medicine* 2020; in press.

<u>In process</u>:

1. **Beskow LM**, Brelsford KM, Hammack-Aviran CM. Use of electronic health records for research recruitment: Researcher, IRB, and provider perspectives; submitted.

2. Bachmann JM, **Beskow LM**, Turer RW, Rice TW, Wallace GH, Rosenbloom ST, Stead WW. Patient-reported outcome measures in routine clinical practice: practical guidance for Institutional Review Boards; in process.

Non-refereed publications:

1. Khoury MJ, **Beskow LM**, Gwinn M. Translation of genomic research into health care [letter]. *JAMA* 2001; 285(19): 2447.

2. **Beskow LM**. Considering the nature of individual research results [invited commentary]. *American Journal of Bioethics* 2006; 6(6): 38-40.

3. **Beskow LM**, Dame L, Costello EJ. Certificates should be retired, Certificates should be strengthened [author reply]. *Science* 2009; 323(5919): 1288-90.

4. **Beskow LM**. Genotype-driven recruitment and the disclosure of individual research results [invited commentary]. *American Journal of Bioethics* 2017; 17(4): 64-5.

5. **Beskow LM**, Lindsell CJ, Rice TW. Consent for acute care research and the regulatory "gray zone" [invited commentary]. *American Journal of Bioethics* 2020; 20(5): 26-8.

Chapters in books:

1. **Beskow LM**, Gwinn M, Rothstein MA. Integrating genetics into public health policy and practice. In RA Goodman, RE Hoffman, W Lopez, GW Matthews, MA Rothstein (eds), *Law in Public Health Practice*. New York, NY: Oxford University Press, 2002.

2. **Beskow LM**. Ethical, legal, and social issues in the design and conduct of human genome epidemiologic studies. In MJ Khoury, J Little, W Burke (eds), *Human Genome Epidemiology: A Scientific Foundation for Using Genetic Information to Improve Health and Prevent Disease*. New York, NY: Oxford University Press, 2003.

3. Haga S, **Beskow LM**. Ethical, legal, and social implications of biobanks for genetics research. In DC Rao (ed), *Genetic Dissection of Complex Traits, Second Edition*. San Diego, CA: Academic Press, 2008.

4. **Beskow LM**, Burke W. Ethical issues in genetic epidemiology and population genetics. In SS Coughlin, TL Beauchamp, DL Weed (eds), *Ethics and Epidemiology, Second Edition*. New York, NY: Oxford University Press, 2009.

5. **Beskow LM**. Informed consent in genomic and personalized medicine. In HF Willard, GS Ginsburg (eds), *Genomic and Personalized Medicine, Second Edition*. San Diego, CA: Elsevier, Inc., 2012.

6. **Beskow LM**, Hammack CM, Brelsford KM, McKenna KC. Thought leader perspectives on risks in precision medicine research. In: IG Cohen, HF Lynch, E Vayena, U Gasser (eds), *Big Data, Health Law, and Bioethics*. Cambridge, UK: Cambridge University Press, 2018.

7. **Beskow LM**, Fullerton SM, Burke W. Ethical issues in genetic epidemiology and population genetics. In SS Coughlin, A Dawson (eds), *Ethics and Epidemiology, Third Edition*. New York, NY: Oxford University Press, forthcoming.

Non-authored publications (selected examples of formal acknowledgement in publication):

- Millikan R. The changing face of epidemiology in the genomics era. *Epidemiology* 2002; 13: 472-80.

- Grosse SD, Wordsworth S, Payne K. Economic methods for valuing the outcomes of genetic testing: beyond cost-effectiveness analysis. *Genetics in Medicine* 2008; 10: 648-54.

- Henderson GE. Introducing social and ethical perspectives on gene—environment research. *Sociological Methods & Research* 2008; 37: 251-76.

- Obeid J, Gabriel D, Sanderson I. A biomedical research permissions ontology: cognitive and knowledge representation considerations. *Proceedings of the 2010 Workshop on Governance of Technology, Information and Policies* 2010; Austin, Texas, USA.

- Resnik DB. Genomic research data: Open vs. restricted access. *IRB: Ethics & Human Research* 2010; 32: 1-6.

- Ross LF, Loup A, Nelson RM, et al. Human subjects protections in community-engaged research: a research ethics framework. *Journal of Empirical Research on Human Research Ethics* 2010; 5: 5-17.

- Ross LF, Loup A, Nelson RM, et al. The challenges of collaboration for academic and community partners in a research partnership: points to consider. *Journal of Empirical Research on Human Research Ethics* 2010; 5:19-31.

- Ross LF, Loup A, Nelson RM, et al. Nine key functions for a human subjects protection program for community-engaged research: points to consider. *Journal of Empirical Research on Human Research Ethics* 2010; 5: 33-47.

- Wolf LE, Bouley TA, McCulloch CE. Genetic research with stored biological materials: ethics and practice. *IRB: Ethics & Human Research* 2010; 32: 7-18.

- McGuire AL, Oliver JM, Slashinski MJ, et al. To share or not to share: A randomized trial of consent for data sharing in genome research. *Genetics in Medicine* 2011; 13: 948-55.

- Maschke KJ. Returning genetic research results: considerations for existing no-return and future biobanks. *Minnesota Journal of Law, Science & Technology* 2012; 13: 559-73.

- Obeid JS, Gerken K, Madathil KC, et al. Development of an electronic research permissions management system to enhance informed consents and capture research authorizations data. *AMIA Joint Summits on Translational Science Proceedings* 2013; 189-93.

- McCormick JB, Sharp RR, Ottenberg AL, et al. The establishment of research ethics consultation services: an emerging research resource. *Clinical & Translational Science* 2013; 6: 40-4.

- Robinson JO, Slashinski MJ, Wang T, et al. Participants' recall and understanding of genomic and large-scale data sharing. *Journal of Empirical Research on Human Research Ethics* 2013; 8: 42-52.

- Wolf LE, Patel MJ, Williams BA, et al. Certificates of Confidentiality: Protecting human subject research data in law and practice. *Minnesota Journal of Law, Science & Technology* 2013; 14: 11-87.

- Kinsella K (ed). *Issues in Returning Individual Results from Genome Research Using Population-Based Banked Specimens, with a Focus on the National Health and Nutrition Examination Survey.* Washington, DC: The National Academies Press; 2014.

- Kost RG, Lee LN, Yessis JL, et al. Research participant-centered outcomes at NIH-supported clinical research centers. *Clinical & Translational Science* 2014; 7: 430-40.

- Mester JL, Mercer M, Goldenberg A, et al. Communicating with biobank participants: Preferences for receiving and providing updates to researchers. *Cancer Epidemiology, Biomarkers & Prevention* 2015; 24: 708-12.

- Check DK. Investigating racial disparities in quality of chemotherapy-induced side effect management among Medicare beneficiaries with early-stage breast cancer. The University of North Carolina at Chapel Hill, ProQuest Dissertations Publishing, 2016. 10119959.

- Smith ME, Sanderson SC, Brothers KB, et al. Conducting a large, multi-side survey about patients' views on broad consent: challenges and solutions. *BMC Medical Research Methodology* 2016; 16: 162

- Sanderson SC, Brothers KB, Mercaldo ND, et al. Public attitudes toward consent and data sharing in biobank research: a large multi-site experimental survey in the US. *American Journal of Human Genetics* 2017; 100: 414-27.

- Weinfurt KP, Bollinger JM, Brelsford KM, et al. Comparison of approaches for notification and authorization in pragmatic clinical research evaluating commonly used medical practices. *Medical Care* 2017; 55: 970-8.

- Gelinas L, Weissman J, Lynch HF, et al. Oversight of patient centered outcomes research: recommendations from a Delphi panel. *Annals of Internal Medicine* 2018; 169: 559-63.

- Doerr M, Grayson S, Moore S, et al. Implementing a universal informed consent process for the *All of Us* Research Program. *Pac Symp Biocomput*. 2019; 24: 427-38.

- Wolf LE, Brown EF, Kerr R, et al. The web of legal protections for participants in genomic research. *Health Matrix* 2019; 29(1).

Other:

a. Selected abstracts:

- Peppercorn JM, Hamilton EP, Qiu S, Lipkus I, Marcom PK, **Beskow LM**, Lyman GH. Practice and attitudes towards CYP2D6 testing for patients on tamoxifen among US Oncologists [conference abstract]. *Cancer Research* 2009; 69: 563S.

- Peppercorn JM, Hamilton EP, **Beskow LM**, Lipkus I, Marcom PK, Lyman GH. Factors influencing use of genetic tests in clinical practice among US oncologists [conference abstract]. *Journal of Clinical Oncology* 2010; 28: Abstract 6067.

- Peetz AB, Patel MB, Guillamondegui OD, Dennis BM, Betzold RD, Streams JR, Gunter O, Karp SJ, **Beskow LM**, Meador KG. Resuscitating the dying for organ donation: a statewide survey of trauma surgeons [conference abstract]. *Journal of the American College of Surgeons* 2019; 229(4): e18.

b. Editorials, position, and background papers:

- **McConnell LM**. Who should take the Alzheimer's test? [editorial] *Stanford Medicine* Winter 1998/99: 13.

- Wolf LE, Brown EF, **Beskow LM**. If we don't own our genes, what protects study subjects in genetic research? *The Conversation* 2016; https://theconversation.com/if-we-dont-own-our-genes-what-protects-study-subjects-in-genetic-research-56003.

- Wolf LE, **Beskow LM**. DNA databases, cracking crimes, and confidentiality. *Bill of Health* 2020; https://blog.petrieflom.law.harvard.edu/2020/02/14/dna-databases-cracking-crimes-and-confidentiality-genomic.

Professional Activities – Extramural

Federal workshops:

1. Invited Participant and Speaker, "Genotype-Tissue Expression (GTEx) Resource" workshop, National Institutes of Health, Bethesda, MD, June 2008.

2. Invited Participant and Speaker, "Ethical and Practical Guidelines for Reporting Genetic Research Results to Study Participants" workshop, National Heart, Lung & Blood Institute, Bethesda, MD, January 2009.

3. Invited Participant and Speaker, "Release of Research Results to Participants in Biospecimen Studies" workshop, National Cancer Institute, Bethesda, MD, July 2010.

4. Co-Chair (with Jim Evans), CDC / National Center for Health Statistics Workshop to develop disclosure criteria for return of individual genomic research results to participants in the National Health and Nutrition Examination Survey (NHANES), 2011.

5. Invited Participant, "Establishing a Central Resource of Data from Genome Sequencing Projects" workshop, National Institutes of Health, Bethesda, MD, June 2012.

6. Invited Participant and Panelist, "The Future of the eMERGE Network" workshop, National Human Genome Research Institute, Bethesda, MD, January 2014.

7. Invited Participant and Panelist, “Defining Research Needs and Assessing Implications for Research of the ACMG Recommendations for Incidental Findings in Clinical Genome Sequencing” workshop, National Human Genome Research Institute, Bethesda, MD, February 2014.

8. Invited Participant and Speaker, “Guidelines for Returning Individual Results from Genome Research Using Population-Based Banked Specimens” workshop, National Academy of Sciences, Washington, DC, February 2014.

9. Invited Participant and Speaker, “Federal Research Regulations and Reporting Requirements” committee meeting, National Academy of Sciences, Engineering, and Medicine, Houston, TX, October 2015.

10. Invited Participant and Speaker, “Return of Results in the *All of Us* Research Program, National Institutes of Health, Bethesda, MD, March 2017.

Federal grant review panels:

1. Special Emphasis Panel for RFA GD08-801, “Genomic Applications in Practice and Prevention: Translation Programs in Education, Surveillance, and Policy,” Centers for Disease Control & Prevention, July 2008.

2. Special Emphasis Panel for RFA-HG-09-004, “Follow-up Consultation to Inform the Design of a Possible Longitudinal Cohort Study of the Role of Genes and Environment in Health and Disease,” National Human Genome Research Institute, March 2009.

3. Special Emphasis Panel for RFA-OD-09-003, “NIH Challenge Grants in Health and Science Research (RC1),” National Institutes of Health, June 2009.

4. Source Evaluation Group for Solicitation S10-084, “Cancer Human Biobank (caHUB) Acquisition of Normal Tissues” and Solicitation S10-120, “caHUB Acquisition of Normal Tissues in Support of the Genotype-Tissue Expression (GTEx) Project,” National Cancer Institute, Office of Biorepositories and Biospecimen Research, March-April, 2010.

5. Special Emphasis Panel for RFA-HG-12-005, “Specialized Centers of Excellence in ELSI Research (CEER) (P50)” and RFA-HG-12-012, “Exploratory Centers of Excellence in ELSI Research (CEER) (P20),” National Human Genome Research Institute, November 2012.

6. Special Emphasis Panel for RFA-RM-13-005, “Human Heredity and Health in Africa (H3Africa): Ethical, Legal, and Societal Issues (ELSI) Research Program (U01),” NIH Common Fund, July 2014.

7. Special Emphasis Panel for RFA-HG-17-006, “Centers of Excellence in Ethical, Legal, Social Implications (ELSI) Research (CEER) (RM1),” National Human Genome Research Institute, March 2018.

8. Initial Review Group, “Genome Research Review Committee,” National Human Genome Research Institute, March 2020.

9. Special Emphasis Panel/Scientific Review Group, “Societal and Ethical Issues in Research,” National Institutes of Health, March 2020.

Other federal activities:

1. Member, Ethics Working Group, National Children’s Study, 2000-2002.

2. Member, Subpart A Subcommittee, Secretary's Advisory Committee for Human Research Protections, U.S. Department of Health and Human Services, 2010-2012.

3. Co-Chair (with Lisa Carey), Correlative Science Working Group, Concise Informed Consent Template Project, Cancer Therapy Evaluation Program, National Cancer Institute, 2011.

4. Federal Advisory Committee, National Children’s Study, National Institutes of Health, 2012-2015.

5. Informed Consent Working Group, NIH Precision Medicine Initiative Cohort Program, 2016-2017.

6. Return of Value Committee, *All of Us* Research Program, NIH Precision Medicine Initiative, 2017-2018.

7. Omics Committee, *All of Us* Research Program, NIH Precision Medicine Initiative, 2017-present.

8. Committee on Access, Privacy and Security, *All of Us* Research Program, NIH Precision Medicine Initiative, 2018-present.

9. Genomics Consent Working Group, *All of Us* Research Program, NIH Precision Medicine Initiative, 2019.

10. ELSI Brain Trust, *All of Us* Research Program, NIH Precision Medicine Initiative, 2019-present.

Other extramural activities:

1. Member, Committee on Privacy, Blue Ribbon Panel on Human Genetic Technologies, National Conference of State Legislatures; contributing author on “Genetics Policy Report: Privacy,” 2002.

2. Advisory Board, “Ethics and Practice of Stored Tissue Genetic Research,” an NCI-sponsored study (PI: Leslie E. Wolf, Georgia State University), 2007.

3. Member, Informed Consent Working Group, Association of American Medical Colleges, 2007-2008.

4. Chair, Research Ethics Consultation Workgroup, Clinical Research Ethics Key Function Committee, Clinical and Translational Science Award (CTSA) Consortium, 2007-2009.

5. Advisory Board, “The Ethics of Consent for the Public Release of Potentially Identifiable DNA Data,” an NHGRI-sponsored study (PI: Amy L. McGuire, Baylor College of Medicine), 2007-2010.

6. Member, Clinical Research Ethics Key Function Committee, CTSA Consortium, 2007-2012.

7. Team Lead, Informed Consent Task Force, Consent and Community Consultation Workgroup, Electronic Medical Records and Genomics (eMERGE) Network, 2008-2011 (member: 2007-2011)

8. Co-Chair (with Ross McKinney), Scholarly Collaboration on Research Ethics (SCORE) Workgroup, Clinical Research Ethics Key Function Committee, CTSA Consortium, 2009-2010 (member: 2009-2012).

9. Advisory Committee, Biobanks Working Group, Clinical Research Ethics Key Function Committee, CTSA Consortium, 2010-2012.

10. Working Group, “Managing Incidental Findings and Research Results in Genomic Biobanks & Archives,” an NHGRI-sponsored study (PI: Susan M. Wolf, University of Minnesota), 2010-2011.

11. Ethics Advisor, “Epi4K: Gene Discovery in 4,000 Epilepsy Genomes,” an NINDS-sponsored study (PI: David B. Goldstein, Duke University), 2011-2015.

12. Working Group, “Disclosing Genomic Incidental Findings in a Cancer Biobank,” an NCI-sponsored study (PI: Gloria M. Petersen, Mayo Clinic), 2011-2016.

13. Center Investigator, “Adaptive Leadership for Cognitive/Affective Symptom Science (ADAPT),” an NINR-funded Center of Excellence for Symptom Science Research (PIs: Ruth Anderson and Sharron Docherty, Duke University School of Nursing), 2012-2017.

14. Advisor, “Patient Perspectives on Broad Consent in Biobank Research,” an NHGRI-funded administrative supplement for the Electronic Medical Records and Genomics (eMERGE) Network, Consent, Education, Regulation, and Consultation workgroup, 2013-2014.

15. Advisor, “Incidental Findings in Whole Genome Sequencing Research: Assessing the Roadblocks to Translation,” George Washington University School of Medicine and Health Sciences Emerging Scholars Grant (PI: Shawneequa Callier, George Washington University), 2015-2016.

16. EMR Research Recruitment Working Group, Methods & Processes Domain Task Force, CTSA Consortium, 2015-2017.

17. Advisor, informed consent process for the Precision Medicine Initiative Cohort Program, “Direct Volunteers Pilot Studies,” an NIH-funded study (PI: Joshua Denny, Vanderbilt University), 2016.

18. Advisory Board, “Sharing Qualitative Research Data: Identifying and Addressing Ethical and Practical Barriers,” an NHGRI-funded study (PI: James DuBois, Washington University), 2017-present.

19. Member, Data Safety and Monitoring Board, “Preliminary Investigation of optimaL Oxygen Targets (PILOT) Trial,” an NHLBI-funded study (PI: Matthew Semler, Vanderbilt University Medical Center), 2018-present.

20. BioVU Ethics Advisory Board and Operations Oversight Board, Vanderbilt University Medical Center, 2018-present.

21. Working Group, “Genetic Data Sharing in Frontotemporal Lobar Dementia” (PIs: Jalayne Arias and Jennifer Yokoyama, University of California San Francisco), 2020.

Professional Activities – Intramural

1. Member, Research Committee, Department of Health Policy & Administration, UNC-Chapel Hill School of Public Health, 2003-2005.

2. Chair, Offering Individual and Aggregate Research Results Subcommittee, Ad Hoc Committee on Tissue Banks and DNA Repositories, UNC-Chapel Hill, 2005-2008.

3. Advisory Committee on “Whole Genome Sequencing Research – IRB Considerations,” Duke University, Durham, NC, 2007.

4. Team Lead, Regulatory and Compliance Working Group, Duke Biobank Task Force, 2007-2008.

5. Oversight Committee, Measurement to Understand Reclassification of Disease of Cabarrus/Kannapolis (MURDOCK) Study, Duke University, 2007-2009.

6. Community Engagement Committee, MURDOCK Study, Duke University, 2008-2010.

7. Duke Biobanking Ethics and Regulations Working Group, Duke University, 2010-2016.

8. IGSP Working Committee on Translation and Applications of Genomics, Duke University, 2011.

9. Chair, Ad Hoc Human Genetics Review Committee, Duke University, 2013-2017 (member, 2011-2013).

10. Member, Center for Effective Health Communication, Vanderbilt University Medical Center, 2017-present.

11. Member, Faculty Appointments and Promotions Committee, Department of Health Policy, Vanderbilt University Medical Center, 2018-present.

12. Member, Vanderbilt Genetics Institute, Vanderbilt University Medical Center, 2020-present.

Professional Activities – Other (selected examples)

- Medical Scientific Advisory Council, Alzheimer's Association of the Greater San Francisco Bay Area, 1998.

- Invited Participant, "Day of Dialog" Workshop for the development of the National Health Museum, San Francisco, CA, October 1998.

- Invited Reviewer, "Pharmacogenetics: Ethical and Regulatory Issues in Research and Clinical Practice," a report of the Consortium on Pharmacogenetics, 2002.

- Invited Reviewer, University of Washington Center for Genomics and Public Health, "Asthma Genomics: Implications for Public Health," a report commissioned by the Centers for Disease Control and Prevention, 2004.

- Invited Participant, "Reporting Results of Genetic Research" workshop, Stanford University Center for Integration of Research on Genetics and Ethics, Stanford, CA, July 2005.

- Consultant, Duke Center for Community Research, "Ethics and Community-Engaged Research," a Collaborative Institutional Training Initiative (CITI) research ethics education module, 2009.

- Consultant, consent form for the Cancer Prevention and Research Institute of Texas (CPRIT)-funded Texas Cancer Research Biobank, Baylor College of Medicine, 2010-2011.

- Consultant, consent form for the LAM Treatment Alliance Biobank, 2011.

- Invited Reviewer, "Informed Consent for Genomics Research" web resource (http://www.genome.gov/informedconsent), National Human Genome Research Institute, August 2014.

- Invited Participant, "Ethical, Legal, and Social Implications of Electronic Consent" workshop, RTI International, Research Triangle Park, NC, April 2016.

- Invited Reviewer, updated NCI Informed Consent Template, Cancer Therapy Evaluation Program, National Cancer Institute, August 2016.

- Consultant, Delphi process to identify metrics for evaluating ethical and regulatory aspects of Patient-Centered Clinical Research, Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics, Harvard Law School, November 2017.

- Invited Reviewer, *The Oxford Handbook of Research Ethics*, Oxford University Press, 2019.

Journal referee:

American Journal of Bioethics; AJOB Empirical Bioethics (formerly AJOB Primary Research); American Journal of Critical Care; American Journal of Epidemiology; American Journal of Human Genetics; American Journal of Managed Care; American Journal of Medical Genetics; American Journal of Pharmacogenomics; American Journal of Preventive Medicine; American

Journal of Public Health; Annals of Behavioral Medicine; BMC Health Services Research; BMC Medical Ethics; BMC Medical Genomics; Canadian Medical Association Journal; Clinical Trials; Community Genetics; Contemporary Clinical Trials; Critical Reviews in Oncology/Hematology; European Journal of Human Genetics; Genetic Epidemiology; Genetics in Medicine (*Top Reviewer 2013); Genome Research; Health Affairs; Health Education & Behavior; IRB: Ethics & Human Research; JAMA; Journal of Empirical Research on Human Research Ethics; Journal of Genetic Counseling; Journal of Law, Medicine & Ethics; Journal of the National Cancer Institute; Narrative Inquiry in Bioethics; Nature Biotechnology; Neuroepidemiology; North Carolina Medical Journal; Optometry & Vision Science; Science; Science Translational Medicine; Trends in Genetics

- Consulting Editor, *Journal of Empirical Research on Human Research Ethics*, 2010-present

- Editorial Board, *Ethics & Human Research*, 2018-present

Professional Awards and Special Recognitions

1. Public Health Traineeship Grant, 1994-1995; Recipient, Boston University School of Public Health Scholarship, 1995-1996.

2. Wyeth-Ayerst Scholarship for Women in Graduate Medical and Health Business Programs, 1994-1995 and 1995-1996.

3. Career Development Award, “Integration of Human Genetics into Public Health Education and Training,” Association of Teachers of Preventive Medicine, 1999-2001.

4. Graduate School Merit Assistantship, University of North Carolina at Chapel Hill, 2001-2002.

5. Pre-Doctoral Fellowship in Cancer Prevention and Control, Cancer Control and Education Program (funded by the National Cancer Institute, R25-CA-57726), UNC Lineberger Comprehensive Cancer Center, 2003-2004 and 2004-2005.

6. Ann Geddes Stahlman Chair in Medical Ethics, Vanderbilt University Medical Center, 2018-present.

Presentations at Scientific Meetings

1. *Genetic Testing and Alzheimer Disease* at “Genetic Information: Acquisition, Access, and Control,” University of Central Lancashire for the International Association of Bioethics and Euroscreen, Preston, England, December 1997.

2. *Genetic Testing and Alzheimer Disease: Ethical, Legal, and Social Implications of Clinical Testing Programs* at “Advances in the Practice of Clinical Genetics,” 5th Annual Meeting of the American College of Medical Genetics, Los Angeles, CA, March 1998.

3. *Targeted Prevention: A New Paradigm in Public Health Practice* at “Individual Genetic Variation: Implications of the Coming Transformation of Medicine,” Stanford Program in Genomics, Ethics, and Society, Stanford, CA, October 1998.

4. *Evaluating the Safety and Effectiveness of Genetic Tests* for the Office of Genetics and Disease Prevention, Centers for Disease Control and Prevention, Atlanta, GA, January 1999.

5. *APOE Genotyping for the Diagnosis of Alzheimer Disease* at the Kaiser Regional Ethics Symposium on Genetics, Berkeley, CA, March 1999.

6. *Integrating Genetics into Public Health Research: Developing Guidelines for Informed Consent* for the Excellence in Science Committee, Centers for Disease Control and Prevention, Atlanta, GA, November 1999.

7. *Genetic Research: Guidance from the National Bioethics Advisory Commission* at "Prevention 2000," 17th Annual National Preventive Medicine Conference, Atlanta, GA, March 2000.

8. *Translating Advances in Human Genetics into Public Health Action* at Alabama Public Health Association Annual Meeting, Auburn, AL, April 2000.

9. *The Role of Genetics in Public Health Prevention Programs* at "Genetics in Public Health: Connecting Research, Education, Practice and Community," 3rd National Conference on Genetics and Disease Prevention, Ann Arbor, MI, September 2000.

10. *Protecting Participants in Population-Based Research Involving Genetics* at "Ethics, Law and Policy," 5th World Congress of Bioethics, London, England, September 2000.

11. *Patient Contact Studies: Results from a National Survey* at "From Registration to Research," Maryland Cancer Registry 2005 Educational Conference, Baltimore, MD, December 2005.

12. *NIH's Proposal for Data Sharing in Genomic Studies: Exploring the Implications for Participants, Investigators, and IRBs* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, Washington, DC, November 2006.

13. *Access to Potential Subjects in Epidemiological and Health Services Research: Considerations for IRBs* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, Washington, DC, November 2006.

14. *Informed Consent for Biobanks: Research to Translate Policy into Practice* at "Translating 'ELSI': Ethical, Legal, and Social Implications of Genomic Research," Cleveland, OH, May 2008.

15. *Ethical and Policy Issues in Large-Scale Research Repositories and Data Sharing* at "Genotype-Tissue Expression (GTEx) Resource," National Institutes of Health Workshop, Bethesda, MD, June 2008.

16. *Research Participants' Reactions to Biorepository Consent Language* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, Orlando, FL, November 2008.

17. *Informed Consent Disclosures and Options Concerning Genetic Research Results* at "Ethical and Practical Guidelines for Reporting Genetic Research Results to Study Participants," National Heart, Lung & Blood Institute Workshop, Bethesda, MD, January 2009.

18. *CEER-CTSA Synergies* at the 5th Annual Meeting of the Centers of Excellence in ELSI Research (CEER), Stanford, CA, March 2009.

19. *Certificates of Confidentiality and the Compelled Disclosure of Research Data,* a National Institute of Environmental Health Sciences Seminar, Research Triangle Park, NC, April 2009.

20. *Simplifying Informed Consent: Stakeholder Perspectives* at the American Society of Human Genetics Annual Meeting, Honolulu, HI, October 2009.

21. *Biobanks' Handling of Incidental Findings and Individual Research Results* at "Managing Incidental Findings and Research Results in Genomic Biobanks & Archives" Workshop, Minneapolis, MN, January 2010.

22. *Research on Simplifying Consent for Biobanking* at Subpart A Subcommittee Meeting, Secretary's Advisory Committee on Human Research Protections, Rockville, MD, June 2010.

23. *Offering Individual Genetic Research Results: Context Matters* at "Release of Research Results to Participants in Biospecimen Studies," National Cancer Institute Workshop, Bethesda, MD, July 2010.

24. *Improving Informed Consent* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, San Diego, CA, December 2010.

25. *Biological Specimens, Biobanking, and Informed Consent Issues* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, San Diego, CA, December 2010.

26. *Disclosing Individual Research Results in Genotype-Driven Research Recruitment: IRB Perspectives* at ELSI Congress: Exploring the ELSI Universe, Chapel Hill, NC, April 2011.

27. *The Use and Understanding of Certificates of Confidentiality* at "Research with Vulnerable Populations: Charting the Ethical Terrain," National Institute of Mental Health Ethics Conference, St. Louis, MO, June 2011.

28. *Participant Perspectives on Data Sharing* at "Challenges in Research Ethics and Policy: Perspectives on Data Sharing," NHGRI/EMERGE Conference, Bethesda, MD, July 2011.

29. *Ethical Approaches to Genotype-Driven Research Recruitment* at the 12th International Congress of Human Genetics/American Society of Human Genetics Annual Meeting, Montreal, Québec, Canada, October 2011.

30. *Certificates of Confidentiality: Uses and Understanding* at U.S. Department of Health & Human Services' Certificate Coordinators' Meeting, Bethesda, MD, October 2011.

31. *Certificates of Confidentiality: Everything You Wanted to Know but Were Afraid to Ask* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, National Harbor, MD, December 2011.

32. *Adopting Personalized Medicine: Identifying Policy and Educational Strategies* at "At the Interface of Clinical Research and Clinical Medicine," Duke Center for Personalized Medicine Symposium, Durham, NC, March 2012.

33. *Informed Consent in Biobanking and Biorepositories* at "Engaging the Community for Research Success: What Scientists and IRBs Need to Know," South Atlantic National Research Conference, Raleigh, NC, March 2012.

34. *Consent to Disclosure of Research Results and Incidental Findings to Family Members: Points to Consider* at "Disclosing Genomic Incidental Findings in a Cancer Biobank" Workshop, Minneapolis, MN, May 2012.

35. *To Return or Not To Return: Individual Research Results and the Role of Biobanks* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, San Diego, CA, December 2012.

36. *Informed Consent and Cluster-Randomized Trials* at "Ethical and Regulatory Issues in Pragmatic Cluster Randomized Trials" workshop, NIH Health Care Systems Research Collaboratory, Bethesda, MD, July 2013.

37. *Informed Consent: Elevating the Process and Improving the Form* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, Boston, MA, November 2013.

38. *Research Participants' Attitudes and Preferences* at "Guidelines for Returning Individual Results from Genome Research Using Population-Based Banked Specimens" workshop, National Academy of Sciences, Washington, DC, February 2014.

39. *Simplifying Informed Consent* for Weekly Rounds, AstraZeneca Oncology, online webinar, June 2014.

40. *Return of Genetic Research Results to Participants and Families: IRB Perspectives and Roles* at "Should We Offer Genomic Research Results to a Participant's Family, Including After the Participant's Death," Minneapolis, MN, November 2014.

41. *Participant Perspectives on Research Use of Electronic Health Records* at "Federal Research Regulations and Reporting Requirements" committee meeting, National Academy of Sciences, Engineering, and Medicine, Houston, TX, October 2015.

42. *Developing a Participant-Centric Consent Process for ADAPTABLE* for NIH Collaboratory Grand Rounds: Rethinking Clinical Research, online webinar, February 2016.

43. *Developing a Participant-Centric Consent Process for ADAPTABLE* at RTI International, Research Triangle Park, NC, April 2016.

44. *Improving Biobank Consent Comprehension: Insights from a National Randomized Survey* at the American Society of Human Genetics Annual Meeting, Vancouver, British Columbia, Canada, October 2016.

45. *Evaluating Approaches to Biobank Consent: Implications for Future Solutions* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, Anaheim, CA, November 2016.

46. *Individual Genomic Research Results and Informed Consent* at "Return of Results in the *All of Us* Research Program" workshop, National Institutes of Health, Bethesda, MD, March 2017.

47. *Informed Consent: Content, Communications, and Emerging Technologies* at Office for Human Research Protections' "Research Community Forum," Harvard Medical School, Cambridge, MA, May 2018.

48. *Challenges in Sharing and Re-Using Qualitative Data: Context Matters*, 20th Annual Conference, American Society of Bioethics and Humanities, Anaheim, CA, October 2018.

49. *Exploring Understanding of 'Understanding': The Paradigm Case of Biobank Consent Comprehension*, Association for the Accreditation of Human Research Protection Programs webinar (with Carol Weil), February 2019.

Teaching Activities

Academic and community-based lectures:

1. *Genetic Testing for Breast Cancer Susceptibility* (with Sara Tobin) at "Molecular Genetic Methods," Cold Spring Harbor-sponsored workshop at Foothill College, Los Altos Hills, CA, April 1997.

2. *Ethical Issues in Molecular Genetics* (with Sara Tobin and Timothy Caulfield) for Earthwatch Student Challenge Program, Stanford Human Genome Center, Palo Alto, CA, July 1997.

3. *Ethics and Alzheimer Genetics* (with Sara Tobin) for the Bay Area Alzheimer's Consortium, San Mateo, CA, October 1997.

4. *Ethical Issues in Genetic Testing for Alzheimer Disease* for Alzheimer's Association Support Group, San Francisco, CA, March 1998.

5. *Ethical Implications of Advances in Human Genetics* for the Center for Advancement and Renewal of Educators, San Francisco, CA, March 1998.

6. *Implications of Advances in Molecular Genetics* (with Sara Tobin) for Earthwatch Student Challenge Program, Stanford Human Genome Center, Palo Alto, CA, August 1998.

7. *Assessing Health Care Technologies: Using Genetic Information to Improve Health & Prevent Disease* for "Evolution, Organization, and Financing of Health Services in the United States" (HPAA 220), UNC-Chapel Hill School of Public Health, November 2000.

8. *Ethical and Policy Issues in Genomics and Public Health*: Guest lectures for "Ethical Issues in Health Policy and Administration" (HPAA 185), UNC-Chapel Hill School of Public Health, February 2002, February 2003, February 2004.

9. *Recruiting Research Participants through Cancer Registries—Stakeholder Perspectives:* Dissertation presentations for Duke Institute for Genome Sciences & Policy, September 2006; RTI International, April 2006; UNC Center for Excellence in Ethical, Legal & Social Implications Research, April 2006; Indiana University Center for Health Services and Outcomes Research, August 2005; Policy Seminar in Health Policy and Administration (HPAA 360), UNC-Chapel Hill School of Public Health, April 2004.

10. *NIH's Proposed Data Sharing Policy for Genome-Wide Association Studies* for the Cardiovascular Genomic Forum, Duke Institute for Genome Sciences & Policy, Durham, NC, October 2006.

11. *Ethical & Policy Issues in Research Involving Human Biospecimens* for the Genome Academy, Duke Institute for Genome Sciences & Policy, Durham, NC, November 2006.

12. *Large-Scale Research Involving Genomics* for the Clinical Research Training Program's Responsible Conduct of Research Course, Duke University School of Medicine, Durham, NC, April 2007.

13. *Research Ethics Consultation in the Clinical and Translational Science Awards (CTSA) Consortium* at "Research Ethics Consultation" workshop, Stanford University Center for Integration of Research on Genetics & Ethics, Stanford, CA, May 2007.

14. *Large-Scale Genomic Databases: Practical and Policy Considerations for Use* for Genomes@4 series, Duke Institute for Genome Sciences & Policy, Durham, NC, May 2007.

15. *Simplifying Informed Consent for Biorepositories* for the Genomic Medicine Forum, Duke Institute for Genome Sciences & Policy, Durham, NC, February 2008.

16. *Gene Expression to Stratify Cancer Patients and Predict Clinical Outcome: Scientific and ELSI Issues in the Cancer Genome Atlas Project* (panel) for the UNC-Chapel Hill Center Genomics & Society interdisciplinary seminar series, Chapel Hill, NC, April 2008.

17. *Returning Research Results to Research Participants* for the Duke University Genome Revolution Focus Program, Durham, NC, September 2008.

18. *Researchers' Obligations to Disclose Genetic Research Results to Research Participants: What Do You Think?* for the Genomic Medicine Forum, Duke Institute for Genome Sciences & Policy, Durham, NC, December 2008.

19. *Genetic Databases and Privacy Concerns* (with Lauren Dame) for the Responsible Conduct of Research Forum, Duke University Graduate School, Durham, NC, February 2009.

20. *Informed Consent for Biospecimen Research* for the Duke University Health System Institutional Review Board, Durham, NC, December 2009.

21. *Simplifying Informed Consent for Biospecimen Research* for the UNC-Chapel Hill Center Genomics & Society interdisciplinary seminar series, Chapel Hill, NC, December 2009.

22. *Research on Simplifying Consent for Biobanking* for the Genomic Medicine Forum, Duke Institute for Genome Sciences & Policy, Durham, NC, February 2010.

23. *Genetic Databases and Privacy Concerns* (with Lauren Dame) for the Responsible Conduct of Research Forum, Duke University Graduate School, Durham, NC, February 2010.

24. *Research on Simplifying Consent for Biobanking* for the Measurement to Understand Reclassification of Disease of Cabarrus/Kannapolis (MURDOCK) Study Healthcare Advisory Board, Kannapolis, NC, April 2010.

25. *Ethical Issues in Genotype-Driven Research Recruitment* for the Duke Institute for Genome Sciences & Policy Annual Retreat, Durham, NC, November 2010.

26. *Disclosing Individual Research Results in Genotype-Driven Research Recruitment* (with Emily Namey) for the Trent Center for Bioethics, Humanities & History of Medicine works-in-progress seminar series, Duke University Medical Center, Durham, NC, February 2011.

27. *Genotype-Driven Research Recruitment: Research Participants' Reflections on Return of Results* (with Jean Cadigan and Marsha Michie) for the UNC-Chapel Hill Center Genomics & Society interdisciplinary seminar series, Chapel Hill, NC, March 2011.

28. *Challenges and Opportunities in Informed Consent for Biobanking* for the Columbia University Center for Research on Ethical/Legal/Social Implications of Psychiatric, Neurologic & Behavioral Genetics, New York, NY, March 2013.

29. *Ethical Approaches to Genotype-Driven Research Recruitment* for the New York University School of Medicine PI Lecture Series, New York, NY, June 2013.

30. *Empirical Bioethics* for the Duke Clinical Research Institute faculty meeting, Durham, NC, August 2013.

31. *Ethical Issues in the Research Use of Electronic Health Records* for Research Ethics Grand Rounds, UNC Center for Bioethics, Office of Human Research Ethics, and NC TraCS, Chapel Hill, NC, May 2015.

32. *Ethical Issues in the Research Use of Electronic Health Records* for the Southeastern Diabetes Initiative meeting, Duke Translational Medicine Institute, Durham, NC, June 2015

33. *Developing a Participant-Centric Consent Process for ADAPTABLE* for the Duke Clinical Research Institute Research Conference, Durham, NC, October 2015.

34. *Empirical Bioethics and the Mysterious Case of "Informed" Consent* for the Duke Clinical Research Institute Research Conference, Durham, NC, February 2016.

35. *Empirical Bioethics and Precision Medicine Research*, Center for Biomedical Ethics and Society, Vanderbilt University, Nashville, TN, March 2017.

36. *Empirical Bioethics and the Research Use of Electronic Health Records,* Center for Biomedical Ethics and Society, Vanderbilt University, Nashville, TN, October 2017.

37. *Empirical Research in Bioethics*, for the Vanderbilt University Medical Center Ethics Committee, Nashville, TN, February 2018.

38. *Thought Leader Perspectives on Unregulated Research Using mHealth Devices,* Center for Biomedical Ethics and Society, Vanderbilt University Medical Center, Nashville, TN, April 2018.

39. *eConsent for Biobanking: Exploring Understanding of "Understanding,"* keynote speaker for Center for Effective Health Communication Research Forum, Vanderbilt University Medical Center, October 2018.

40. *Medical Research Ethics*, Foundations of Medical Knowledge Learning Communities context lecture, Vanderbilt University Medical Center, Nashville, TN, January 2019.

41. *Accountability and Integrity in Publication of Biomedical Research*, Academy of Investigators workshop, Digestive Disease Research Center, Vanderbilt University Medical Center, Nashville, TN, March 2019.

42. *Research Ethics and the Role of Informed Consent*, Foundations of Medical Knowledge Learning Communities context lecture, Vanderbilt University Medical Center, Nashville, TN, January 2020.

43. *Certificates of Confidentiality*, Genetic Privacy and Identity in Community Settings (GetPreCiSe) All-Hands meeting, Vanderbilt University Medical Center, Nashville, TN, March 2020.

44. *Research Recruitment Using Electronic Health Records: Stakeholder Perspectives*, Health Policy Grand Rounds, Vanderbilt University Medical Center, Nashville, TN, April 2020.

Courses, workshops, and committees:

1. Teaching Assistant (as graduate student) for courses on *Ethical Issues in Health Policy and Administration* and on *Health Law*, UNC-Chapel Hill School of Public Health, 2002-2003 (Instructor: Dean Harris, JD).

2. Co-instructor of 5-week course, *Responsible Conduct of Research for NIH Trainees*, Duke University, Durham, NC, March 2009. My lecture: "Study Design and Ethical Research with Humans."

3. Co-instructor of 5-week course, *Responsible Conduct of Research for NIH Trainees*, Duke University, Durham, NC, September 2009. My lecture: "Responsible Authorship and Peer Review."

4. Instructor of day-long course, *Examining Complex Issues in Genomics Research*, Centers for Disease Control & Prevention, Atlanta, GA, March 2011.

5. Mentor, *Grant Writing Workshop*, Office for Faculty Mentoring, Duke University School of Medicine, Durham, NC, July 2015.

6. Allan Peetz, MD, MPH Program Mentorship Committee, Department of Health Policy, Vanderbilt University School of Medicine, 2018-present.

Research Program

Areas of research interest:

Research ethics, including issues in human subjects protections and regulations, research recruitment, informed consent, privacy and confidentiality, data sharing, return of research results to participants

Public/population health, genetics/genomics, biobanking, electronic health records, cancer, learning healthcare systems, pragmatic trials

Empirical bioethics methods, including quantitative and qualitative techniques to elicit data to inform policy and practice

External support – gifts, grants, and contracts:

PAST:

UL1-RR-024128 PI: Robert Califf, Duke University 2006 – 2012

Duke Translational Medicine Institute

Objective: To support the translation of fundamental discoveries to care delivery to global health

My Role: Member, Research Ethics Core

P50-HG-003391 PI: Robert Cook-Deegan, Duke University 2006 – 2015

Center for Public Genomics 2.0 (a Center of Excellence in ELSI Research (CEER))

Objective: To gather and analyze information about the role of publication, data sharing, materials-sharing, patenting, database protection, and other practices that affect information flow in genomics research and development

My Role: Investigator (2006-10); PI of "Linkages" Core (2011-15)

UL1-RR-024128* PI: Laura Beskow 2007 – 2008

Informed Consent for Biorepositories

Objective: To gather data from prospective participants concerning their understanding and opinions about the information conveyed in a biorepository consent form

My Role: Principal Investigator

**Internal funding from Duke Translational Medicine Institute (R. Califf, PI)*

UL1-RR-024128* PI: Geoff Ginsburg, Duke University 2008 – 2009

CTSA National Resource Database for Translational (T1) Research

Objective: To develop a framework to collect and share information regarding capabilities, cores, facilities, resources, and skills that are aligned with the needs of T1 investigators in order to enable more effective translational research

My Role: Investigator

**Supplement to UL1-RR-024128 (R. Califf, PI)*

MURDOCK Study* PI: Laura Beskow 2008 – 2009

Simplifying Informed Consent for Biorepositories

Objective: To develop a simplified biorepository consent form by gathering data from research subjects, researchers, and IRBs

My Role: Principal Investigator (with Kevin Weinfurt, Duke University)

**Internal funding from a David H. Murdock Foundation gift to Duke University (R. Califf, PI)*

RC2-CA-148041 PI: Geoff Ginsburg, Duke University 2009 – 2010

Programs in Clinical Effectiveness of Cancer Pharmacogenomics

Objective: To develop and apply tools and methods for evidence based evaluation of genomic and personalized medicine applications in cancer care

My Role: Investigator

RC2-LM-010796 PI: Jay Moskowitz, Health Sciences South Carolina 2009 – 2011

An Open Source Research Permissions Management System for South Carolina

Objective: To create a novel and comprehensive mechanism for managing informed consents and privacy authorizations for research, and to implement it widely in South Carolina

My Role: PI of Duke subcontract (with Kevin Weinfurt, Duke University)

RC1-HG-005787 PI: Laura Beskow 2009 – 2012

Ethical Approaches to Genotype-Driven Research Recruitment

Objective: To develop evidence-based guidelines for addressing the ethical issues that arise in genotype-driven re-contact and research recruitment

My Role: Principal Investigator

R01-HG-005087 PI: Laura Beskow 2010 – 2013

Assessing the Use and Understanding of Certificates of Confidentiality

Objective: To examine how research institutions understand and use Certificates in protecting research participants and the role they play in assessments of risk

My Role: Principal Investigator

Duke University* PI: Laura Beskow 2012 – 2013

Institutional Challenges and Opportunities in Clinical Genome Sequencing

Objective: To elucidate the complex challenges and opportunities presented by the emergence of clinical genomic sequencing at academic medical centers

My Role: Principal Investigator (with Sharron Docherty, Duke University)

**Competitive internal funding from the Duke Institute for Genome Sciences & Policy*

R01-HG-005691 PI: Leona Cuttler, Case Western 2012 – 2014

Advancing Collaborative Genetic Research: Ethical and Policy Challenges

Objective: To improve collaborative genetic research through the study of areas of concordance and variation in institutions' policies and practices for human subjects' protection in biobanking

My Role: PI of Duke Subcontract

R01-HG-006621 PI: Laura Beskow 2012 – 2017

Enhancing the Biobanking Informed Consent Process to Improve Comprehension

Objective: To develop and assess biobank consent process that involves simplified form and interactive test-feedback procedure to enhance comprehension

My Role: Principal Investigator (with Kevin Weinfurt, Duke University)

U54-AT-00774 PI: Adrian Hernandez, Duke University 2012 – 2017

Health Care Systems Research Collaboratory — Coordinating Center

Objective: To improve the way clinical trials are conducted by creating a new infrastructure for collaborative research with healthcare systems

My Role: Member, Research Ethics Core

Duke University* PI: Laura Beskow 2013 – 2014

Empirical Bioethics Interdisciplinary Colloquium

Objective: To engage leaders in a variety of fields around Duke to discuss emerging ethical issues at the frontiers of biomedical research, and to identify ethical questions that could benefit from collaborative empirical study

My Role: Principal Investigator (with Kevin Weinfurt, Duke University)

**Competitive internal funding from the Duke University School of Medicine*

U54-AT-007748* PI: Kevin Weinfurt, Duke University 2013 – 2015

Health Care Systems Research Collaboratory—Empirical Ethics Supplement

Objective: To improve understanding of when and how stakeholders believe research testing interventions that are considered standard of care are acceptable and when consent for it should be sought

My Role: Investigator

**Supplement to U54-AT-007748 (A. Hernandez, PI)*

UL1-TR-001117 PI: Ebony Boulware, Duke University 2013 – 2017

Duke Clinical & Translational Science Institute

Objective: To create an integrated home for clinical and translational research at Duke by providing infrastructure and resources to serve investigators and trainees across the research spectrum

My Role: Member, Research Ethics Core

AS-1502-27081 (PCORnet) PI: Matthew Roe, Duke University 2015 – 2016

Optimal Maintenance Aspirin Dose for Patients with Coronary Artery Disease

Objective: To compare the effectiveness of two doses of aspirin currently in widespread use in a secondary-prevention population of patients with cardiovascular disease

My Role: Investigator

R01-LM-012178 PI: Laura Beskow 2014 – 2018

Ethical Approaches to Research Use of Clinical Records and Data

Objective: To gather empirical data regarding patients' willingness to share their clinical data for research use, and their reactions to researcher contact based on the results of EHR phenotyping, and to systematically develop recommendations regarding the ethical use of clinical data for research

My Role: Principal Investigator

R01-HG-007733 PI: Laura Beskow 2014 – 2018

Beyond Data Security: Promoting Confidentiality and Advancing Science

Objective: To gather empirical data regarding the actual scope of the confidentiality protections applicable to genome research (beyond basic security measures), as well as how these are and should be described to prospective participants

My Role: Principal Investigator

U2-COD-023196* PI: Consuelo Wilkins, Vanderbilt University 2018 – 2019

***All of Us* Research Program Engagement Core**

Objective: To facilitate meaningful involvement of diverse participant communities in governance and oversight of the *All of Us* Research Program by recruiting participants with a wide range of perspectives to provide feedback and input on aspects of the Research Program, developing and testing methods of engagement, and assessing the impact of engagement

My Role: Investigator

**Funded through U2-COD-023196 (J. Denny, PI)*

Greenwall Foundation* PI: Alexander Langerman, Vanderbilt University 2017 – 2019

Ethical Analysis of Overlapping Surgery

Objective: To examine the common practice of "overlapping surgery"—when a surgeon leaves one operation to operate on another patient, leaving a resident or assistant to continue non-critical parts of the first surgery

My Role: Advisor

**Greenwall Foundation "Making a Difference" Program*

VUMC Internal Funding PI: Dan Benedetti, Vanderbilt University 2019 – 2020

Pediatric Oncologists' Experiences with Treatment Refusal

Objective: To describe pediatric oncologists' experiences, knowledge, and resources to address treatment refusal, non-adherence, and abandonment

My Role: Advisor

R01-CA-207538 PI: Mark Rothstein, University of Louisville 2017 – 2020

Addressing ELSI Issues in Unregulated Health Research Using Mobile Devices

Objective: To conduct comprehensive analyses and develop consensus recommendations regarding the protection of participants in unregulated health research using mobile devices

My Role: PI of Vanderbilt subcontract

PRESENT:

U2-COD-023196 PI: Joshua Denny, Vanderbilt University 2017 – 2021

***All of Us* Research Program Data and Research Support Center**

Objective: To serve as a hub for the *All of Us* Research Program, leading the optimization of participant engagement strategies, robust data infrastructure, facilitative support of researchers, coordination and communication between the diverse stakeholders of the Program

My Role: Investigator

UL1-TR-002243 PI: Gordon Bernard, Vanderbilt University 2017 – 2022

Vanderbilt Institute for Clinical & Translational Research (VICTR)

Objective: To create a highly functional and integrated clinical and translational research infrastructure, raising the quality and scientific rigor of the research conducted at Vanderbilt and Meharry Medical College and leveraging the unique resources and expertise within VICTR's Hub to contribute to the mission of the CTSA program

My Role: Investigator

R01-HG-009914 PI: Mark Rothstein, University of Louisville 2018 – 2021

Regulation of International Direct-to-Participant Genomic Research

Objective: To analyze applicable legal provisions and recommend measures to enable ethical, international, direct-to-participant research

My Role: PI of Vanderbilt subcontract

RM1-HG-009034 PI: Brad Malin, Vanderbilt University 2019 – 2020

Genetic Privacy and Identity in Community Settings (GetPreCiSe)

Objective: To enhance understanding of the impact of threats to privacy and identity in genomic data; to measure the efficacy of efforts to protect privacy and identity; to develop models to quantify the probability of genomic data re-identification and harm; to address concerns by developing interventions and policy solutions.

My Role: Investigator

VUMC Internal Funding PI: Ricky Shinall, Vanderbilt University 2019 – 2022

Palliative Care-SCOPE Trial

Objective: To assess the effect of early palliative care consultation on recovery, survival, and end-of-life care following surgery for abdominal cancer.

My Role: Advisor

R01-CA-230352 PI: Daniel Barocas, Vanderbilt University 2019 – 2022

10-year Comparative Effectiveness and Harms of Treatments for Prostate Cancer

Objective: To expand upon an established population-based cohort of men diagnosed with localized prostate cancer, by collecting 10-year clinical and patient-reported information that will enable comparisons of oncologic and quality of life outcomes among the treatment options.

My Role: Investigator

R21-HG-010952 PI: Laura Beskow 2019 – 2021

Exploring Choice of Law Challenges in Multi-Site Precision Medicine Research

Objective: To begin exploring stakeholders' experiences and opinions regarding choice of law questions in the research context, as well as whether and how existing choice of law frameworks might be applied in resolving them.

My Role: Principal Investigator (with Leslie Wolf, Georgia State University)

PENDING:

NIH RM1 PI: Brad Malin, Vanderbilt University Submitted Jul 2019

Genetic Privacy and Identity in Community Settings (GetPreCiSe) – Renewal

My Role: Investigator

NIH U01 PI: Dan Roden, Vanderbilt University Submitted Aug 2019

Electronic Medical Records and Genomics (eMERGE IV) Network

My Role: Investigator

NIH U01 PI: Laura Beskow, Vanderbilt University To be submitted

Risk Assessment and Consent for Enrollment in Acute Care Research

My Role: Principal Investigator (MPI)

NIH U2C PI: Ben Ho Park, Vanderbilt University To be submitted

Participant Engagement and Cancer Genome Sequencing

My Role: Principal Investigator (MPI)