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## CURRICULUM VITAE

### **Personal Information**

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### **Education**

1982-1984 Post-doctoral Fellowship, University of North Carolina at Chapel Hill, School of Public Health. Course work in the Departments of Epidemiology, Health Behavior and Health Education, and Health Policy and Administration.

1977-1982 Ph.D. University of Michigan, Department of Sociology; Ann Arbor, Michigan. Dissertation Title: *Danwei, The Chinese Work Unit: A Participant-Observation Study of a Hospital*. 1982. 295 pages. Dissertation research conducted at a hospital in the People's Republic of China: a case study of hospital organization, the delivery of health care, and the socialist system of workplace organization.

1976-1977 M.A. University of Michigan, Department of Sociology; Ann Arbor, Michigan

1975-1976 Course requirements for an M.A. in Chinese Studies completed, University of Michigan, Center for Chinese Studies; Ann Arbor, Michigan

1967-1971 B.A. Oberlin College, Department of Chinese Language and Literature; Oberlin, Ohio

### **Employment History**

July 1, 2009-2015 Chair, Department of Social Medicine

July 2008-2011 Director, Ethics Core, UNC Translational and Clinical Sciences Institute (NC TraCS)

October 2007  
To present Director, UNC Center for Genomics and Society

July 2004-2014 Director, International Core, UNC Center for AIDS Research

Nov. 11, 1999  
To present Professor  
Department of Social Medicine

School of Medicine  
University of North Carolina at Chapel Hill

Responsibilities include teaching in the medical school curriculum, in several graduate medical education programs, and advising independent student research projects. Topics include social factors in health and health care, cross cultural issues in medical and research ethics, the ethics and politics of clinical research, and ethical, legal, and social implications of genetic and genomic research. Scholarship includes interdisciplinary survey research on the determinants of health, health and equity in China, surveys evaluating informed consent in clinical and epidemiological research, studies of perceptions of risk and benefit in genetic and genomic research, and in early phase HIV “cure” trials, and mixed methods research on organizational and policy features of biobanks in the US.

1996- to present      Adjunct Professor  
Department of Sociology  
University of North Carolina at Chapel Hill

1993-1999            Associate Professor  
Department of Social Medicine  
School of Medicine  
University of North Carolina at Chapel Hill

1987-1993            Assistant Professor  
Department of Social Medicine  
School of Medicine  
University of North Carolina at Chapel Hill

1983-1987            Research Assistant Professor (half time appointment)  
Department of Social Medicine  
School of Medicine  
University of North Carolina at Chapel Hill

1980-1981            Program Coordinator  
Orange County Women's Center  
Chapel Hill, North Carolina

Responsibilities included program development and conducting a needs assessment survey of the women of Orange County.

1980                    Interpreter for IBM sales and technical representatives, Beijing

1979-1980            Special Representative of the Yale-China Association, New Haven, Connecticut

To conduct a feasibility study for bio-medical exchange programs between Yale University School of Medicine and Hubei Provincial Medical College.

- 1979-1980            Lecturer, Hubei Provincial Medical College, Wuhan  
Department of Foreign Languages  
People's Republic of China
- 1975-1978            Research Assistant in Chinese Politics  
University of Michigan Center for Chinese Studies, for Prof. Michel Oksenberg. Work  
during this time resulted in publication of an index to editorials in The People's Daily.
- 1972-1973            Translator  
National Palace Museum  
Taipei, Taiwan (5 months)
- 1971-1973            Instructor  
Department of Foreign Languages  
Tunghai University, Taichung, Taiwan

### **Honors & Awards**

Member, Genome Canada Expert Review Panel, November 2017- July 2018

Kenan Senior Faculty Research and Scholarly Leave, January-July 2017

Outstanding Postdoc Mentor Award, September 2016

Member, NHGRI National Advisory Council, 2016-2020

Member, NHGRI Genomics and Society Working Group, 2016-2020

*Annual Review of Genomics and Human Genetics*, Editorial Board, 2015-2016

Fellow, Academic Leadership Program, UNC Institute for Arts and Humanities, 2010-2011

*Genetics in Medicine*, Editorial Board, 2009-2017

Member, Protection of Human Subjects Committee, Family Health International, RTP, NC, 2006-2008

*American Sociological Review*, Editorial Board, 2001-2004

NIH, NHLBI, Genetics of Asthma and Hypertension Observational Study Monitoring Board, 2001-2005

Member, NHGRI Ethical Legal & Social Implications Program Study Section, 2001-2005

Pogue Leave, awarded by the Chancellor of the University of North Carolina, for a sabbatical leave, 1997-1998

Mellon Fellowship in Chinese Studies, for post-doctoral studies in the fields of public health and medical sociology, at the University of North Carolina School of Public Health, sponsored by the American Council of Learned Societies and the Social Science Research Council, 1982-1984

University of Michigan Center for Chinese Studies Dissertation Grant, 1979-1980

National Defense Foreign Language Fellowships, University of Michigan Center for Chinese Studies, 1976-79

Newton Prize, Oberlin College received for publication of article, "Sexism in the Chinese Language," 1974

Oberlin Shansi Memorial Association Fellowship, awarded for two years' teaching English in Taiwan and one year in residence at Oberlin College, 1971-1974

## **Publications**

### Books & Journal Supplements

- 2023 Nancy M.P. King, Larry R. Churchill, and Gail E. Henderson, Re-Envisioning Bioethics: A Path toward Health Justice UNC Press, Chapel Hill, NC.
- 2014 Henderson, Gail E., Guest Editor, Contextualizing HIV/STI in China: Interdisciplinary Studies in a South China City, AIDS and Behavior Vol. 18, Supplement 2, February. 120 pages.
- 2005 Nancy M.P. King, Ronald P. Strauss, Larry R. Churchill, Sue E. Estroff, Gail E. Henderson, and Jonathan Oberlander (eds), The Social Medicine Reader, Second Edition, Volume I: Patients, Doctors, and Illness Duke University Press, Durham, NC.
- 2005 Henderson, Gail E., Sue E. Estroff, Larry R. Churchill, Nancy M.P. King, Jonathan Oberlander, and Ronald P. Strauss (eds), The Social Medicine Reader, Second Edition, Volume II: The Social Contributions to Health, Difference and Inequality Duke University Press, Durham, NC.
- 2005 Jonathan Oberlander, Larry R. Churchill, Sue E. Estroff, Gail E. Henderson, Nancy M.P. King, and Ronald P. Strauss (eds), The Social Medicine Reader, Second Edition, Volume III: Health Policy, Medicine and Markets Duke University Press, Durham, NC.
- 2000 Entwisle, Barbara and Gail E. Henderson (eds), Re-Drawing Boundaries: Work, Households, and Gender in China. University of California Press, Berkeley. 344 pages.
- 1999 King, Nancy M.P., Gail E. Henderson, and Jane Stein (eds), Beyond Regulations: The Ethics of Human Subjects Research University of North Carolina Press, Chapel Hill. 273 pages.
- 1997 Henderson, Gail E., Nancy M.P. King, Ronald P. Strauss, Sue E. Estroff, and Larry R. Churchill (eds), The Social Medicine Reader Duke University Press, Durham, NC. 516 pages.
- 1984 Henderson, Gail E. and M.S. Cohen, The Chinese Hospital: A Socialist Work Unit Yale University Press, New Haven. 183 pages.

1982 Oksenberg, Michel and Gail E. Henderson, Research Guide to People's Daily Editorials 1948-1975 University of Michigan Center for Chinese Studies, Ann Arbor. 194 pages.

### Book Chapters

- 2019 Meagher, Karen, R. Jean Cadigan, Gail E. Henderson, Eric T. Juengst, "Public Health Genomics, Biobanking, and Ethics," Anna C. Mastroianni, Jeffrey P. Kahn, Nancy E. Kass (editors), The Oxford Handbook of Public Health Ethics. [Available online from Oxford Press]
- 2019 Estroff, Sue E. and Gail E. Henderson, "Social and Cultural Contributions to Health, Differences, and Inequalities," The Social Medicine Reader, Third Edition, Volume II: Differences and Inequalities, Duke University Press, Durham, NC. pp. 3-30.
- 2017 Smith, M. Kumi, Huixin Liu, Junjue Wang, Wensheng He, Gail E. Henderson, William C. Miller, and Ning Wang. "Stigma, sex and family life: Serodiscordance in Henan province, China." In: Persson Asha, Hughes Shana, editors. Cross-Cultural Perspectives on Couples With Mixed HIV Status: Beyond Positive/Negative. Springer International Publishing, New York, pp.125-138.
- 2006 Estroff, Sue E. and Gail E. Henderson, "Social and Cultural Contributions to Health and Illness," The Social Medicine Reader, Second Edition, Volume II: The Social Contributions to Health, Difference and Inequality, Duke University Press, Durham, NC. pp. 4-28.
- 2005 Dongbao Yu and Gail E. Henderson, "Old Problems but New Challenges: Ethics Review and Informed Consent in a Clinical Trial for HIV/AIDS in China," in Ethical Challenges in Study Design and Informed Consent for Health Research in Resource-Poor Settings. Edited by Patricia Marshall. World Health Organization, Geneva.
- 2005 Henderson, Gail E. and Bill Fischer, "Competing in the Chinese Antibiotics Market: Cephalosporins 1982-2000," in The Chinese Pharmaceutical Industry. Edited by Gerhard Sichelstiel. Springer.
- 2001 Henderson, Gail E., "Descriptive Methods: The Case of Genetic Diagnosis," in Methods in Medical Ethics. Edited by Jeremy Sugarman and Daniel P. Sulmasy. Georgetown University Press, Washington DC, pp. 267-385.
- 2000 Henderson, Gail E., Barbara Entwisle, Li Ying, Yang Mingliang, and Zhai Fengying, "The Boundaries of Work (*Gongzuo*): Interviews from Towns and Villages in Hubei Province, 1995," In, Re-Drawing Boundaries: Work, Household, and Gender in China Edited by Barbara Entwisle and Gail Henderson. University of California Press, Berkeley, pp. 33-50.
- 1998 Henderson, Gail E., and T. Scott Stroup, "Preventive Health Care in Zouping: Privatization and the Public Good," In Zouping in Transition: The Political Economy of Growth in a North China County, Edited by Andrew Walder. Council on East Asian Studies, Harvard University, Cambridge, MA, pp. 184-204.

- 1993 Henderson, Gail E., "Physicians in China: Assessing the Impact of Ideology and Organization," The Changing Character of the Medical Profession: An International Perspective. Edited by Frederic W. Hafferty and John McKinlay. Oxford University, New York, pp. 251-278.
- 1992 Henderson, Gail E., "Public Health in China," in China Briefing, 1992. Edited by William A. Joseph. New York: The Asia Society, New York. pp. 103-123.
- 1990 Henderson, Gail E., "Increased Inequality in Health Care in China," In China on the Eve of Tiananmen: Social Consequences of the Chinese Economic Reforms. Edited by D. Davis and E. Vogel. Council on East Asian Studies, Harvard University, Cambridge, MA, pp. 263-282.
- 1989 Henderson, Gail E., "Issues in the Modernization of Medicine in China," In Science and Technology in Post-Mao China. Edited by D.F. Simon and M. Goldman. Published by Council on East Asian Studies, Harvard University, Cambridge, MA, pp. 199-221.

#### Refereed Articles

- 2023 Conley JM, Cadigan RJ, Davis AM, Juengst ET, Kuczynski K, Major R, Stancil H, Villa-Palomino J, Waltz M, Henderson GE. The Promise and Reality of Public Engagement in the Governance of Human Genome Editing Research. American Journal of Bioethics Jul;23(7):9-16.
- 2023 E.A. Okumu, G.E. Henderson, C. Golin, K. Kuczynski, N.Q. Ormsby, H.L. Peay, HIV remission trial investigators' attitudes toward risk and risk mitigation in trials that include treatment interruption, Journal of Virus Eradication Jun 17;9(2):100331. PMC10319831.
- 2023 Peay HL, Rennie S, Henderson GE. Reporting Individual-Level Research Results from Neurocognitive and Psychological Research in People Living with HIV: Lessons from Dementia Research. Curr HIV/AIDS Rep. Jun;20(3):131-138
- 2023 Rennie S, Henderson G, Phanuphak N, Kuczynski K, Colby D, Ormsby N, Kroon E, Hsu D, Likhitwonnawut U, Vasan S, Sacdalan C, Jupimai T, Butterworth O, Peay H. The Essential Need for Trust When Transmission Risk Cannot Be Eliminated in HIV-Remission Trials. Ethics Hum Res. Jul-Aug;45(4):2-15..
- 2022 Henderson, GE, What Bioethicists Still Need to Know about the Social Determinants of Health and Why, Special Issue in Perspectives in Biology and Medicine, Edited by Larry R. Churchill and Elizabeth Lanphier. 65(4):664-671.
- 2022 Cadigan, R.J., Waltz, M., Henderson, G.E., Conley, J.M., Davis, A.M., Major, R., Juengst, E.T. Scientists' Views on Scientific Self-Governance for Human Genome Research. Human Gene Therapy. Nov;33(21-22):1157-1163. PMC9700337.
- 2022 Isaacson S, Kuczynski K, Ormsby N, Peay HL, Rennie S, Cadigan RJ, Kroon E, Phanuphak N, Ananworanich J, Vasan S, Jupimai T, Prueksakaew P, Henderson GE. Decision making for

- invasive and non-invasive optional procedures within an acute HIV research cohort in Bangkok. Contemp Clin Trials Commun. Dec 23;31: 101054. PMC9829688
- 2022 Peay HL, Rennie S, Cadigan RJ, Gwaltney A, Jupimai T, Phanuphak N, Kroon E, Colby DJ, Ormsby N, Isaacson SC, Vasan S, Sacdalan C, Prueksakaew P, Benjapornpong K, Ananworanich J, Henderson GE. Attitudes About Analytic Treatment Interruption (ATI) in HIV Remission Trials with Different Antiretroviral Therapy (ART) Resumption Criteria. AIDS Behav. May;26(5):1504-1516. PMC9007833
- 2022 Kimberly S Foss, Julianne M O'Daniel, Jonathan S Berg, Sabrina N Powell, R. Jean Cadigan, Kristine J Kuczynski, Laura V Milko, Katherine W Saylor, Megan C Roberts, Karen Weck, Gail E Henderson, The Rise of Population Genomic Screening: Characteristics of Current Programs and the Need for Evidence Regarding Optimal Implementation, in Journal of Precision Medicine, Apr 26;12(5):692, PMC9145687, Special Issue Ethics in Expanding Precision Medicine to Population Health
- 2021 King NMP, Henderson GE, Churchill LR, "Beyond the Medical Model: Retooling Bioethics for the Work Ahead," American Journal of Bioethics Feb;21(2):53-55.
- 2021 Waltz M, Juengst ET, Edwards T, Henderson GE, Kuczynski KJ, Conley JM, Della-Penna P, Cadigan RJ. The View from the Benches: Scientists' Perspectives on the Uses and Governance of Human Gene-Editing Research. CRISPR Journal Aug;4(4):609-615. PMC8392077.
- 2021 Asao Noda, Kazuto Kato, Chieko Tamura, Leslie G Biesecker, Misa Imaizumi, Yusuke Inoue, Gail E Henderson, Benjamin Wilfond, Kaori Muto, Mariko Naito, Junji Kayukawa, Ethical, legal and social implications of human genome studies in radiation research: a workshop report for studies on atomic bomb survivors at the Radiation Effects Research Foundation, Journal of Radiation Research, rrab043, <https://doi.org/10.1093/jrr/rrab043>
- 2020 Conley JM, Davis AM, Henderson GE, Juengst ET, Meagher KM, Walker RL, Waltz M, Cadigan J. A New Governance Approach to Regulating Human Genome Editing. N C Journal of Law and Technology. Dec;22(2):107-141. PMC8565716.
- 2020 Henderson GE, Rennie S, Corneli A, Peay HL. Cohorts as collections of bodies and communities of persons: insights from the SEARCH010/RV254 research cohort, International Health Nov 9;12(6):584-590. PMC 7650957.
- 2020 Peay HL, Ormsby NQ, Henderson GE, Jupimai T, Rennie S, Siripassorn K, Kanchawee K, Isaacson S, Cadigan RJ, Kuczynski K, Likhitwonnawut U. Recommendations from Thai stakeholders about protecting HIV remission ('cure') trial participants: report from a participatory workshop. International Health Nov 9;12(6):567-574. PMC 7650909.
- 2020 Henderson GE, Rennie S, Corneli A, Meagher K, Cadigan RJ, Kroon E, Ananworanich J, Peay HL. Parallel but connected: Nuances of conducting behavioral and social science research alongside ethically challenging HIV remission trials. Contemporary Clinical Trials Communication. Jun 16;19:100594. PMC 7322675

- 2020 Churchill, Larry R., Nancy NMP King, Gail E. Henderson, "The Future of Bioethics: It Shouldn't take a Pandemic," Hastings Center Report 50(3):54-56
- 2020 Henderson GE, Ewing M, Kuczynski KJ, Cadigan RJ, Waltz M, Butterfield R, Rini C, Weck K, Berg J, Edwards TP, Development and Validation of a Measure of Comprehension of Genomic Screening—Negative Results (CoG-NR). European Journal of Human Genetics Oct;28(10):1394-1402. PMC7608237
- 2020 Waltz M, Meagher KM, Henderson GE, Goddard KA, Muessig K, Berg JS, Weck KE, Cadigan RJ, Assessing the implications of positive genomic screening results. Personalized Medicine. Mar 17(2):101-109. PMC7147673
- 2020 Mollison L, O'Daniel JM, Henderson GE, Berg JS, Skinner D, Parents' perceptions of personal utility of exome sequencing results. Genetics in Medicine 22,4:752-757. PMC7192542
- 2020 Rini C, Henderson GE, Evans JP, Berg JS, Foreman AKM, Griesemer I, Waltz M, O'Daniel JM, Roche MI, Genomic knowledge in the context of diagnostic exome sequencing: changes over time, persistent subgroup differences, and associations with psychological sequencing outcomes. Genetics in Medicine 22,1:60-68. PMC6946868
- 2019 Rennie, Stuart, Suzanne Day, Allison Mathews, Adam Gilbertson, WK Luseno, Joseph D. Tucker, Gail E. Henderson, "The Role of Inclusion Benefits in Ethics Committee Assessment of Research Studies," Ethics of Human Research Ethics, May 41,3: 13-22.
- 2019 Henderson, Gail E, Margaret Waltz, Karen Meagher, R. Jean Cadigan, Thidarat Jupimai, Sinéad Isaacson, Nuchanart Q Ormsby, Donn J. Colby, Eugène Kroon, Nittaya Phanuphak, Jintanat Ananworanich, Holly L. Peay (2019, "Going off ART in a Closely Monitored HIV "Cure" Trial: Longitudinal assessments of acutely-diagnosed trial participants and decliners," Journal of the International AIDS Society March 22,3:e25260. PMC 6416664.
- 2019 Butterfield, Rita M, James P. Evans, Christine Rini, Kristine J. Kuczynski, Margaret Waltz, R. Jean Cadigan, Katrina A. B. Goddard, Kristin R. Muessig, and Gail E. Henderson, "Returning negative results to individuals in a genomic screening program: lessons learned," Genetics in Medicine 21,2:409-416.
- 2019 Corneli, Amy, Karen Meagher, Gail E. Henderson, Holly L. Peay, Stuart Rennie, "How Biomedical HIV Prevention Trials Incorporate Behavioral and Social Sciences Research: A Typology of Approaches," AIDS and Behavior. Aug;23(8):2146-2154. PMC6647486
- 2018 Coltart CEM, Hoppe A, Parker M, Dawson L, Amon JJ, Simwinga M, Geller G, Henderson G... Ethics in HIV Phylogenetics Working Group. Ethical considerations in global HIV phylogenetic research. Lancet HIV Nov;5(11):e656-e666.



- 2018 Juengst, Eric T, Gail E. Henderson, Rebecca L. Walker, John M. Conley, Douglas MacKay, Karen M. Meagher, Kate Saylor, Margaret Waltz, Kristine J. Kuczynski, R. Jean Cadigan, “Is Enhancement the Price of Prevention in Human Gene Editing? CRISPR Journal 1:351-354.
- 2018 Roche, Myra I, Ida Griesemer, Cynthia M Khan, Elizabeth Moore, Feng Chang Lin, Julianne M O'Daniel, A. Kate M Foreman, Kristy Lee, Bradford C Powell, Jonathan S Berg, James P Evans, Gail E Henderson, Christine Rini, “Factors influencing NCGENES research participants' requests for non-medically actionable secondary findings.” Genetics in Medicine. Sep 21
- 2018 Skinner, Debra, Myra Roche, Karen E. Weck, Kelly A. Raspberry, A. Kate Foreman, NT Strande, Jonathan Berg James P Evans, Gail E. Henderson, "Possibly Positive or Certainly Uncertain?: Participants' responses to uncertain diagnostic results from exome sequencing,” Genetics in Medicine 20,3:313-319.
- 2018 Meagher, Karen M, Eric T. Juengst, and Gail E. Henderson, “Grudging Trust and the Limits of Trustworthy Biorepository Curation,” American Journal of Bioethics 18,4: 23-25.
- 2018 Henderson, Gail E, Holly L. Peay, Eugene Kroon, R Jean Cadigan, Karen Meagher, Thidarat Jupimai, Adam Gilbertson, Jill Fisher, Nucharat Q Ormsby, Nitaya Chomchey, Nittaya Phanuphak, Jintanat Ananworanich, Stuart Rennie, “Ethics of Treatment Interruption Trials in HIV Cure Research: Addressing the conundrum of risk/benefit assessment,” Journal of Medical Ethics 44:270–276. PMC 5869463
- 2018 Waltz, Margaret, R. Jean Cadigan, Anya E. R. Prince, Debra Skinner D, Gail E. Henderson, “Age and perceived risks and benefits of preventive genomic screening, Genetics in Medicine 20,9:1038-1044.
- 2018 Rini, Christine, Cynthia M. Khan, Elizabeth Moore, Myra Roche, James P. Evans, Jonathan S. Berg, Bradford C. Powell, Giselle Corbie-Smith, A. Kate Foreman, Ida Griesemer, Kristy Lee, Julianne M. O'Daniel, Gail E. Henderson, The who, what and why of research participants’ intentions to request a broad range of secondary findings in a diagnostic genomic sequencing study, Genetics in Medicine 2018 Jul;20(7):760-769. PMC5920790.
- 2017 Moore Elizabeth G, Myra I Roche, Christine Rini, Edward W Corty, Zahra Girnary, Julianne M O'Daniel, Feng Change Lin, Giselle Corbie-Smith, James P Evans, Gail E Henderson, Jonathan S Berg. Examining the Cascade of Participant Attrition in a Genomic Medicine Research Study: Barriers and Facilitators to Achieving Diversity. Public Health Genomics 20,6:332-342. PMC6112240.
- 2017 Cadigan R. Jean, Rita Butterfield, Margaret Waltz, Kriste J. Kuczynski, Kristin Muessig, Katrina A.B. Goddard, Gail E. Henderson, Online Education and e-Consent for GeneScreen, a Preventive Genomic Screening Study, Public Health Genomics 20(4):235-246. PMC5698149.

- 2017 Reeder-Hayes, Katherine, Gail E. Henderson, Megan C. Roberts, Elizabeth Claire Dees, “Informed Consent and Decision Making Among Participants in Novel-Design Phase 1 Oncology Trials,” Journal of Oncology Practice Oct 13(10).
- 2018 Wolf SM, Amendola LM, Berg JS, Chung WK, Clayton EW, Green RC, Harris-Wai J, Henderson GE, Jarvik GP, Koenig BA, Lehmann LS, McGuire AL, O'Rourke P, Somkin C, Wilfond BS, Burke W. Navigating the research-clinical interface in genomic medicine: analysis from the CSER Consortium. *Genet Med*. 2018 Apr;20(5):545-553. PMC5832495.
- 2017 Prince AE, Cadigan RJ, Henderson GE, Evans JP, Adams M, Coker-Schwimmer E, Penn DC, Van Riper M, Corbie-Smith G, Jonas DE. Is there evidence that we should screen the general population for Lynch syndrome with genetic testing? A systematic review. *Pharmgenomics Pers Med*. 2017 Feb 20;10:49-60. PMC5325104.
- 2017 Cadigan, R Jean, Teresa P. Edwards, Dragana Lassiter, Arlene M. Davis, Gail E. Henderson. “Forward Thinking” in U.S. Biobanking. Genetic Testing and Molecular Biomarkers Mar;21(3):148-154. PMC5367905.
- 2017 Cohn, Elizabeth G, Gail E. Henderson, Paul S. Appelbaum, Distributive Justice, Diversity, and Inclusion in Precision Medicine: What will success look like? Genetics in Medicine 19,2:157-9. PMC5291806.
- 2017 Tan N, Amendola LM, O'Daniel JM, Burt A, Horike-Pyne MJ, Boshe L, Henderson GE, Rini C, Roche MI, Hisama FM, Burke W, Wilfond B, Jarvik GP. Is "incidental finding" the best term?: a study of patients' preferences. Genetics in Medicine. Feb;19(2):176-181. PMC5291803.
- 2016 Green Robert C., Katrina A. Goddard, Laura M. Amendola... Gail E. Henderson et al. for the CSER Consortium, “The Clinical Sequencing Exploratory Research Consortium: Accelerating the evidence-based practice of genomic medicine,” American Journal of Human Genetics 99,1:246. PMC4908179.
- 2016 Henderson, Gail E., “With great (participant) rights comes great (researcher) responsibility,” Genetics in Medicine 18,2:124-5.
- 2016 Adams, Michael C., James P. Evans, Gail E. Henderson, Jonathan S. Berg, “The promise and peril of genomic screening in the general population,” Genetics in Medicine 18,6:593-9.
- 2016 Ma Qingyan, F Wu, Gail E. Henderson, Stuart Rennie, ZC Rich, Yi Cheng, et al., “‘I Can Co-Exist with HIV’: A qualitative study of perceptions of HIV cure among people living with HIV in Guangzhou, China,” Journal of Virus Eradication 2(3): 170-4.
- 2015 Cadigan R. Jean, Daniel K. Nelson, Gail E. Henderson, Anders G. Nelson, Arlene M. Davis, “Public comments on proposed regulatory reforms that would impact biospecimen research: the good, the bad, and the puzzling,” IRB: Ethics and Human Research Sep-Oct: 37,5:1-10.

- 2015 Lassiter, Dragana, R. Jean Cadigan, Kaaren M. Haldeman, Erik Reavely, Gail E. Henderson, "Standardization as performative accountability in biobanking," Biosocieties 1-15.
- 2015 Peay, Holly, Gail E. Henderson, "What motivates participation in HIV cure trials? A call for real-time assessment to improve informed consent," Journal of Virus Eradication 1(2): 51-53  
PMC4392850
- 2015 Henderson, Gail E., "The Ethics of HIV 'Cure' Research: What can we learn from consent forms?" AIDS Research and Human Retroviruses 31(1):56-63. PMC4287120.
- 2015 Khan, Cynthia M., Christine Rini, Barbara Bernhardt, J. Scott Roberts, KD Christensen, James P. Evans, Kyle Brothers, Myra Roche, Jonathan Berg, Gail E. Henderson, "How can psychological science inform research about genetic counseling for clinical genomics sequencing?" Journal of Genetic Counseling 24:193-204.
- 2015 Prince, Anya E.R., Jonathan S. Berg, James P. Evans, Daniel E. Jonas, and Gail E. Henderson, "Genomic Screening of the General Adult Population: How do we assess net benefit?" Genetics in Medicine. (6):441-3. PMC4387105
- 2014 Dube, Karine, Gail E. Henderson, and David Margolis, "Framing expectations in early HIV cure research," Trends in Microbiology Oct 2014; 22(10): 547-549. PMC4201845
- 2014 Tucker, Joseph D, Stuart Rennie, the Social and Ethical Working Group on HIV Cure, "Social and Ethical Implications of HIV Cure Research," AIDS 28(9): 1247-50. PMC407118.
- 2014 Cadigan, R. Jean, Eric Juengst, Arlene M. Davis, Gail E. Henderson, "Underutilization of specimens in biobanks: an ethical as well as a practical concern?" Genetics in Medicine 16(10):738-40.
- 2014 Henderson, Gail E., Susan M. Wolf, Kristine J. Kuczynski, Steven Joffe, Richard R. Sharp, D. Williams Parsons, Bartha M. Knoppers, Joon-Ho Yu, and Paul S. Appelbaum, "The Challenge of Informed Consent and Return of Results in Translational Genomics: Empirical Analysis and Recommendations," Journal of Law, Medicine, and Ethics. NIHMSID 632427
- 2014 Cadigan, R. Jean, Gail E. Henderson, Arlene M. Davis, and Eric Juengst, "Underutilization of Specimens in Biobanks: An ethical as well as practical concern?" Genetics in Medicine. 16, 738-740. NIHMS ID 631300.
- 2014 Henderson, Gail, Suzanne Maman, Yingying Huang, and Suiming Pan, "Social Contexts of Heterosexual Transmission of HIV/STI in Liuzhou City, China." AIDS and Behavior, February; Volume 18 Supplement 2:111-7. PMC4138215
- 2014 Huang, Yingying, Laurie Abler, Suiming Pan, Gail E. Henderson, Xin Wang, Xingliang Yao, William L. Parish, "Population-Based Sexual Behavior Surveys in China: Liuzhou Compared with Other Prefectural Cities," AIDS and Behavior. February; Volume 18 Supplement 2:118-25.

- 2014 Liu, Qian, Kongshao Zhuang, Gail E. Henderson, et al., "The Organization of Sex Work in Low- and High-priced Venues with a Focus on the Experiences of Ethnic Minority Women Working in these Venues," AIDS and Behavior, February; Volume 18 Supplement 2:172-80. PMC3912223
- 2014 Abler, Laurie, Gail Henderson, Xin Wang, Matthew Avery, Ying-xia Zhang, Suiming Pan, "Affected by HIV Stigma: Interpreting Results from a Population Survey of an Urban Center in Guangxi, China." AIDS and Behavior, February; Volume 18 Supplement 2:192-201. PMC3903664.
- 2014 Haldeman, Kaaren M, R. Jean Cadigan, Arlene Davis, Aaron Goldenberg, Gail E. Henderson, Dragana Lassiter, Erik Reavely, "Community Engagement in US Biobanking: Multiplicity of Meaning and Method," Public Health Genomics, 17:84-94. PMID: PMC4038060
- 2014 Edwards, Teresa P., R. Jean Cadigan, James P. Evans, Gail E. Henderson, "Biobanks containing clinical specimens: defining characteristics, policies, and practices," Journal of Clinical Biochemistry, 47(4-5):245-51, PMC395928.
- 2013 Henderson, Gail E, Teresa P. Edwards, R. Jean Cadigan, Arlene M. Davis, Catherine Zimmer, Ian Conlon, Bryan J. Weiner, "Stewardship Practices in U.S. Biobanks," Science Translational Medicine, December 11; 5(215). PMC24337477.
- 2013 Churchill, Larry R., Nancy M.P. King, and Gail E. Henderson, "Why We Should Continue to Worry about the Therapeutic Misconception," Journal of Clinical Ethics. Winter 24,4:381-6.
- 2013 Burke, Wylie, AM Antommaria, Robin Bennett R, Jeffrey Botkin, Ellen W. Clayton, Gail E. Henderson, et al., "Recommendations for Returning Genomic Incidental Findings? We need to talk!" Genetics in Medicine, November; 15,11: 854-9, 2013. PMC3832423.
- 2013 Henderson, Gail E, R. Jean Cadigan, Teresa P. Edwards, et al., "Characterizing biobank organizations in the U.S.: results from a national survey". Genome Medicine, 5 (1):3. PMC3706795.
- 2013 Cadigan, R. Jean, Dragana Lassiter, Kaaren Haldeman, Ian Conlon, Eric Reavely, Gail E. Henderson, "Neglected Ethical Issues in Biobank Management: Results from a US Study. Life Sciences, Society, and Policy, 9:1-13. PMC4228790
- 2012 Weir, Sharon S., M. Giovanna Merli, Jing Li, Anisha D. Gandhi, William W. Neely, Jessie K. Edwards, Chirayath M Suchindran, Gail E. Henderson, Xiang-Sheng Chen, "A Comparison of Respondent-Driven and Venue-Based Sampling of Female Sex Workers in Liuzhou, China," Sexually Transmitted Infections. Dec; 88 Suppl 2:i95-101. PMC3512399.
- 2012 Boyer, Gregory J., Warren Whipple, R. Jean Cadigan, Gail E. Henderson, "Biobanks in the U.S.: How to identify an undefined and rapidly evolving population," Biopreservation and Biobanking. Dec; 10(6): 511-517. PMC4076972

- 2012 Henderson, Gail E., Eric T. Juengst, Nancy M.P. King, Kriste Kuczynski, Marsha Michie, "What Research Ethics Should Learn from Genomics and Society Research: Lessons from the ELSI Congress of 2011," Journal of Law, Medicine, and Ethics. Winter;40(4):1008-24. PMC4103651
- 2012 Michie, Marsha, R. Jean Cadigan, Gail Henderson, Laura Beskow, "Am I a Control? Genotype-driven research recruitment and self-understandings of study participants," Genetics in Medicine December;14(12):983-9. PMC3578310.
- 2012 Li, Jing, Xiang-Sheng Chen, Giovanna Merli, Sharon S. Weir, Gail E. Henderson, "Systematic Differences in Risk Behaviors and Syphilis Prevalence Across Types of Female Sex Workers: A Preliminary Study in Liuzhou, China," Sexually Transmitted Disease 39,3:195-200. PMC3282016.
- 2012 Tucker, Joseph D., Yang Ligang, Yang Bin, Young D, Gail E. Henderson, SJ Huang, HK Lu, Xiang-Sheng Chen, Myron S. Cohen, "Prior HIV Testing Among STD Patients in Guangdong Province, China: Opportunities for Expanding Detection of Sexually Transmitted HIV Infection," Sexually Transmitted Diseases 39, 3: 182-187. PMC3282013.
- 2012 Corneli AL, Sorenson JR, Bentley ME, Henderson GE, Michael Bowling J, Nkhoma J, Moses A, Zulu C, Chilima J, Ahmed Y, Heilig CM, Jamieson DJ, van der Horst C; Breastfeeding, Antiretroviral, and Nutrition Informed Consent Study Group, "Improving Participant Understanding of Informed Consent in an HIV-Prevention Clinical Trial: A Comparison of Methods." AIDS and Behavior 16,2:412-21.
- 2011 Cadigan, R. Jean, Marsha Michie, Gail E. Henderson, Laura Beskow, "The Meaning of Genetic Research Results: Reflections from individuals with and without a known genetic disorder," Journal of Empirical Research on Human Research Ethics.6,4:30-40. PMC3386306.
- 2011 Beskow, Laura M, Emily E. Namey, R. Jean Cadigan, Tracy Brazg, Julia Crouch, Gail E. Henderson, Marsha Michie, Daniel K. Nelson, Holly K. Tabor, Benjamin S. Wilfond, "Research Participants' Perspectives on Genotype-Driven Research Recruitment," Journal of Empirical Research on Human Research Ethics 6,4:3-20. PMC3395316.
- 2011 Henderson, Gail, "Is Informed Consent Broken?" American Journal of Medical Science 342,4:267-72.
- 2011 Michie, Marsha, Gail Henderson, Joanne Garrett, Giselle Corbie-Smith, "'If I could in a small way help': Motivations for and beliefs about sample donation for genetic research," Journal of Empirical Research on Human Research Ethics 6,2:57-70. PMC3313647
- 2011 Cadigan, R Jean, Michele M Easter, Allison W Dobson, Arlene M Davis, Catherine R Zimmer, Rene Sterling, Barbra B Rothschild, Gail Henderson, "That's a good question": University researchers' views on ownership and retention of human genetic specimens." Genetics in Medicine 13,6:569-75. PMC3385643.

- 2011 Wang, Ying, Li B, Pan J, Sengupta S, Emrick, CB, Cohen MS, Henderson GE, “Factors Associated with Utilization of a Free HIV VCT Clinic by Female Sex Workers in Jinan City, Northern China,” *AIDS and Behavior* 15,4:702-10. PMC3140056.
- 2010 Bussey-Jones J, Joanne Garrett, Gail Henderson, Mairead E. Moloney, Connie Blumenthal, Giselle Corbie-Smith, “The Role of Race and Trust in Tissue/Blood Donation for Genetic Research” *Genetics in Medicine* 12,2:116-21. PMC3114600.
- 2009 Schaffer, Rebecca, Gail Henderson, Larry R. Churchill, Nancy MP King, Barbra B. Rothschild, Sarah Lohser, Arlene M. Davis, “Parents’ Online Portrayals of Pediatric Treatment and Research Options.” *Journal of Empirical Research on Human Research Ethics* 4,3:73-87. PMC3366186.
- 2009 Wang, Ying, Bing Li, J. Zheng, Sohini Sengupta, Cathy B. Emrick, Myron S. Cohen, Gail E. Henderson, “Factors Related to Female Sex Workers’ Willingness to Utilize VCT Service: A Qualitative Study in Jinan City, Northern China,” *AIDS and Behavior* 13,5:866-72. PMC2930910.
- 2009 Bussey-Jones, J, Gail Henderson, Joanne Garrett, Mairead Moloney, Connie Blumenthal, Giselle Corbie-Smith, “Asking the Right Questions: Views on Genetic Variation Research among Black and White Research Participants.” *Journal of General Internal Medicine* 24(3):299-304. PMC2642575.
- 2008 Wang, Ruotao and Gail E. Henderson, “Medical Research Ethics in China,” *Lancet* 372: 1867-8. PMC3140065.
- 2008 Henderson, Gail E., “Introducing Social and Ethical Perspectives on Genetics Research to Sociologists Engaged in Gene-Environment Research,” *Sociological Methods and Research* 37: 251.
- 2008 Henderson, Gail E., Joanne Garrett, Jada Bussey-Jones, Mairead Moloney, and Giselle Corbie-Smith, “Great expectations: Views of genetic research participants regarding current and future genetic studies.” *Genetics in Medicine* 10,3:193-200.
- 2008 Corbie-Smith, Giselle, Gail Henderson, Connie Blumenthal, Jessica Dorrance, Sue Estroff, “Conceptualizing Race in Research” *Journal of the National Medical Association* 100,10:1235-43. PMC3057432.
- 2008 Corbie-Smith, Giselle, Connie Blumenthal, Gail Henderson, Joanne Garrett, Mairead Moloney, Robert Sandler, SW Lloyd, Jessica Dorrance, Jane Darter, “Studying Genetic Research Participants: Lessons from the ‘Learning About Research in North Carolina’ study,” *Cancer Epidemiology Biomarkers Prevention* 17,8:2019-24. PMC3037258.
- 2007 Henderson, Gail E., Larry R. Churchill, Arlene M. Davis, et al., “Clinical Trials and Medical Care: Defining the Therapeutic Misconception,” *Public Library of Science-Medicine* 4,11:1735-1738, PMC2082641.
- 2007 Giselle Corbie-Smith, Ishan Williams, Connie Blumenthal, Jessica Dorrance, Sue Estroff, and Gail E. Henderson, “Relationships and Communication in Minority Participation in Research:

- Multidimensional and multidirectional,” Journal of the National Medical Association 99,5:489-98. PMC2576070.
- 2007 Henderson, Gail E., Amy L. Corneli, David B. Mahoney, Daniel K. Nelson, Charles Mwanambo, “Applying Research Ethics Guidelines: The view from a sub-Saharan research ethics committee,” Journal of Empirical Research on Human Research Ethics 2,2:41-48. PMC3140059.
- 2006 Corneli, Amy L., Margaret Bentley, James Sorenson, Gail Henderson, et al., “Using Formative Research to Develop a Context-Specific Approach to Informed Consent for Clinical Trials,” Journal of Empirical Research on Human Research Ethics 1,4:45-60. PMC3140046.
- 2006 Easter, Michele M., Gail E. Henderson, Arlene M. Davis, Larry R. Churchill, Nancy M. P. King, “The Many Meanings of Care in Clinical Research.” In The View From Here: Social Science and Bioethics, editors Raymond DeVries, Leigh Turner, Kristina Orfali, and Charles Bosk. Monograph published by Sociology of Health and Illness in conjunction with Blackwell Publishing.
- 2006 Sterling, Rene, Gail E. Henderson, and Giselle Corbie-Smith, “Race/Ethnicity, Genes, and Health: A review of the literature regarding public willingness to participate in and concerns about genetic research,” American Journal of Public Health 96, 1971-1978. PMC1751820.
- 2006 Henderson, Gail E., Michele M. Easter, Catherine Zimmer, Nancy M.P. King, Arlene M. Davis, Barbra Bluestone Rothschild, Larry R. Churchill, Benjamin S. Wilfond, and Daniel K. Nelson, “Therapeutic Misconception in Early Phase Gene Transfer Trials,” Social Science and Medicine 62,1:239-53. (Epub 2005 Jul 5)
- 2005 Tucker, Joseph D., Gail E. Henderson, Tianfu Wang, Yingying Huang, William Parish, Suiming Pan, Xiangsheng Chen, and Myron S. Cohen, “Surplus Men, Sex Work, and the Spread of HIV in China,” AIDS 19,6:539-547.
- 2005 King, Nancy M.P., Gail E. Henderson, Larry R. Churchill, Arlene M. Davis, Sara Chandros Hull, Daniel K. Nelson, P. Christy Parham-Vetter, Barbra Bluestone Rothschild, Michele M. Easter, Benjamin S. Wilfond, “Consent Forms and the Therapeutic Misconception: The Example of Gene Transfer Research,” IRB: Ethics and Human Research January 2005.
- 2004 Henderson, Gail E., Arlene M. Davis, Nancy M.P. King, Michele M. Easter, Catherine R. Zimmer, Barbra Bluestone Rothschild, Benjamin S. Wilfond, Daniel K. Nelson, and Larry R. Churchill, “Uncertain Benefit: Investigators’ Views and Communications in Early Phase Gene Transfer Trials,” Molecular Therapy 10,2:225-231.
- 2004 Huang, Yingying, Gail E. Henderson, Suiming Pan, and Myron S. Cohen, “HIV/AIDS Risk among Brothel-based Female Sex Workers in China: Assessing the terms, content and knowledge of sex work,” Sexually Transmitted Disease 11:695-700.

- 2004 Henderson, Gail E., Arlene M. Davis, and Nancy M.P. King, "Vulnerability to Influence – A Two-Way Street," Invited Commentary on Levine, C., R. Faden, C. Grady, D. Hammerschmidt, L. Eckenweiler, and J. Sugarman, "The limitations of vulnerability as a protection for human research participants," The American Journal of Bioethics 4,3:50-51
- 2004 Easter, Michele E., Arlene M. Davis, and Gail E. Henderson, "Confidentiality: More than a Linkage File and a Locked Drawer," IRB: Ethics and Human Research 26, 2:1-5
- 2003 Henderson, Gail E., "Understanding the Context of Emerging Pathogens in China," Harvard Asia Quarterly 7,4: 4-8.
- 2003 Churchill, Larry, Daniel Nelson, Gail Henderson, Nancy King, Arlene Davis, Erin Leahey, and Benjamin Wilfond, "Assessing Benefits in Clinical Research: Why Diversity in Benefit Assessment Can Be Risky," IRB: Ethics and Human Research 25, 3:1-7
- 2002 Davis, Arlene M, Sara Hull, Benjamin Wilfond, Christine Grady, and Gail Henderson, "The Invisible Hand in Clinical Research: The study coordinator's critical role in human subjects protection," Journal of Law, Medicine and Ethics, 30:411-419.
- 2002 Henderson, Gail E. and Nancy M. P. King, "Perceived Benefits of Participation in Gene Transfer Research." HemAware, 7, 5: 73-75.
- 2001 Henderson, Gail E. and Nancy M.P. King, "Studying Benefit in Gene Transfer Research," IRB: Ethics and Human Research 23,2:13-15.
- 2000 Cohen, Myron S., G. Ping, Kim Fox, and Gail Henderson, "Sexually Transmitted Diseases in the People's Republic of China in Y2K: Back to the Future." Sexually Transmitted Diseases 27,3:143-5
- 1998 Biddle, Andrea, Robert DeVellis, Gail Henderson, Sarah Fasick, and Marion Danis, "The Health Insurance Puzzle: A New Approach to Assessing Patient Coverage Preferences. Journal of Community Health.23,3:181-94.
- 1998 Henderson, Gail, John Akin, Paul Hutchinson, Jin Shuigao, Jason Deitrich, Wang Jianmin, and Ma Linmao, "Trends in Health Care Utilization in Eight Chinese Provinces, 1989-1993," Social Science and Medicine 47,12:1957-1971.
- 1997 Danis, Marion, Andrea Biddle, Gail Henderson, Joanne M. Garrett, and Robert De Vellis, "Older Medicare Enrolees' Choices for Insured Services," Journal of the American Geriatric Society 45:688-694.
- 1996 Cohen, Myron S., Gail Henderson, Pat Aiello, and Zheng Heyi, "The Eradication of STDs in China," Journal of Infectious Disease 174 (Supplement 2): S223-230.
- 1995 Entwisle, Barbara, Gail Henderson, Susan Short, Jill Bouma, and Zhai Fengying, "Gender and Family Businesses in Rural China," American Sociological Review 60,1: 36-57.



Translated into Chinese in Bian Yanjie, Edward Jow-Ching Tu and Alvin So (ed) Survey Research in Chinese Societies: Methods and Findings (*Huaren Shehui de Diaocha Yanjiu: Fangfa yu Faxian*) Hong Kong: Oxford University Press, 2001.

- 1995 Henderson, Gail, John Akin, Li Zhiming, Jin Shuigao, Wang Jianmin, and Ge Keyou, "The Distribution of Medical Insurance in China," Social Science and Medicine 41,8: 1119-1130.
- 1994 Henderson, Gail, John Akin, Li Zhiming, Jin Shuigao, Ma Haijiang, and Ge Keyou, "Equity and the Utilization of Health Services: Report on an Eight-Province Survey in China," Social Science and Medicine 39,5: 687-699.
- 1991 King, Nancy M.P. and Gail Henderson, "Treatments of Last Resort: Informed Consent and the Diffusion of New Technology" Mercer Law Review 42, 3:1007-1050.
- 1990 Henderson, Gail, "Rethinking the Presence of American Scholars in China," Commentary. Journal of the American Medical Association, 273:992-993.
- 1988 Henderson, Gail, Elizabeth Murphy, Samuel Sockwell, Zhou Jiongliang, Shen Qingrui, and Li Zhiming, "High-Technology Medicine in China: The Case of Chronic Renal Failure and Hemodialysis." New England Journal of Medicine 318:1000-1004.
- 1987 Henderson, Gail, Liu Yuanli, Guan Xiaoming, and Liu Zongxiu, "The Rise of Technology in Chinese Hospitals," International Journal of Technology Assessment in Health Care 253-263.
- 1983 Cohen, M.S. and Gail Henderson, "The Chinese Hospital," Annals of Internal Medicine 99:564-5
- 1983 Cohen, M.S. and Gail Henderson, "Medical Care in the People's Republic of China: Available but Expensive," Annals of Internal Medicine 99:727-728.
- 1982 Henderson, Gail and M.S. Cohen, "Health Care in the People's Republic of China: A View from Inside the System," American Journal of Public Health 72, 11 (November).
- 1982 Parmalee Donna, Gail Henderson and M.S. Cohen, "Medicine Under Socialism: Some Observations on China and Yugoslavia," Social Science and Medicine 16, 15:1389-1396.
- 1981 Henderson, Gail and M.S. Cohen, "Are Biomedical Exchange Programs Inside the People's Republic of China Feasible? Report of Six-Month Study at Hubei Provincial Medical College," Yale Journal of Biology and Medicine 54,1: 11-20.

### Testimony

- 2003 Henderson, Gail, "Myths and Realities: The Context of Emerging Pathogens in China," Testimony before The Congressional-Executive Commission on China, May 12, Washington DC Roundtable on, "Dangerous Secrets: SARS and China's Health Care System" [www.cecc.gov](http://www.cecc.gov)

- 2003 Henderson, Gail, "What Researchers and Subjects Expect in Gene Transfer Research," Presentation to the NIH Recombinant DNA Advisory Committee, Bethesda, Maryland, June 19

### Book Reviews

- 2001 Journal of the New Jersey Medical Society. Review of Ichiro Kawachi, Bruce P. Kennedy, and Richard G. Wilkinson (ed), The Society and Population Health Reader, Volume I: Income Inequality and Health. New York: The New Press, 1999.
- 1996 The China Journal 36: 180-181. Review of Veronica Pearson, Mental Health Care in China: State Policies, Professional Services, and Family Responsibilities. London: Gaskell, 1995.
- 1994 American Journal of Sociology July: 301-303. Review of Renee C. Fox and Judith Swazey, Spare Parts: Organ Replacement in American Society. London: Oxford University Press, 1992.
- 1994 China Quarterly 532-533. Review of China: Long Term Issues and Options in the Health Transition. Washington DC: The World Bank, 1992.
- 1989 Contemporary Sociology. Review of Yuet-Wat Cheung, Missionary Medicine in China: A Study of Two Canadian Protestant Missions in China Before 1983. London and Lanham MD: University Press of America, 1988.
- 1986 International Journal of Epidemiology. Review of S.M. Hillier and J.A. Jewell, Health Care and Traditional Medicine in China. London: Routledge and Kegan Paul, 1984.

### Conferences and Panels Organized

#### Conferences/Workshops

- 2016 Co-organized Workshop, "Who will Benefit from Precision Medicine? Distributive Justice and Dilemmas of Inclusion," with Paul Appelbaum and Liz Cohn, Columbia University, January 8-9
- 2011 & 2012 Organized Two-Part Workshop on Ethical issues in Genomic Research on HIV, with the Office for AIDS Research, NIH, November 5, 2011 and July 21, 2012
- 2011 Organized Workshop on Ethical Considerations in Human HIV Genetics/Genomics Research, Sponsored by NIH and DHHS Office of AIDS Research, Washington DC, November 2-3, as part of OAR GRWG Ethics Workshop Planning Committee
- 2011 Organized Conference on Social Science and Public Health Research on HIV/AIDS in China, Liuzhou City, May 30-June 3, funded by UNC Center for AIDS Research and NICHD R24 grant, "Partnership for Social Science Research on HIV in China"

- 2011 Organized ELSI 2011 Congress, Chapel Hill, NC, April 12-14, Hosted by the UNC Center for Genomics and Society, funded by supplement to our P50 Center grant
- 2010 Organized Training Course on Qualitative Data Analysis, Peoples University, Beijing, China, May 25-30, funded by UNC Center for AIDS Research and NICHD R24 grant, “Partnership for Social Science Research on HIV in China”
- 2008 Organized Training Course on NIH Grantwriting, Peoples University, Beijing, China, December 10-14, funded by UNC Center for AIDS Research and NICHD R24 grant, “Partnership for Social Science Research on HIV in China”
- 2006 Developed and lectured in research ethics workshop in Lilongwe, Malawi, June 13-16, funded by UNC Center for AIDS Research and Fogarty AIDS International Training and Research Program (AITRP)
- 2005 Organized and hosted “Therapeutic Misconception Consensus Conference,” Chapel Hill, NC September 8
- 2003 Developed and lectured in research ethics workshop for HIV/AIDS clinical researchers, Kunming, Yunnan, China, funded by Fogarty AIDS International Training and Research Program (AITRP)
- 2002, 2003 Developed and lectured in research ethics workshop for HIV/AIDS clinical researchers, Beijing, China, funded by Fogarty AIDS International Training and Research Program (AITRP)
- 1996 Organized International Conference (with Barbara Entwisle), “Gender, Households, and the Boundaries of Work in China.” Funded by grants from the American Council of Learned Societies, the Chiang Ching-Kuo Foundation, and the Carolina Population Center.
- 1995 Organized International Working Conference (with UNC Colleagues), “From ‘Regs’ to Relationships: Reexamining Research Ethics.” Funded by the UNC University Center for International Studies, and other UNC departments and centers.

#### Selected Panels

- 2020 “HIV Cure Research,” panel member at International AIDS Society virtual meeting July 6-10.
- 2017 With Holly Peay and Cindy Powell, “Ethical Issues in Large Scale Research: Cross-cutting Issues in Exploring Genetic Risk in Adult and Pediatric Populations,” ELSI Congress, Jackson Labs, Farmington, CT, June 5-7
- 2012 “Who are we to say? Translating results from empirical studies of biobanking into normative recommendations” Panel organized for the American Society for Bioethics and Humanities meeting, Washington DC, October

- 2012 “Social Science Research on STD and HIV/AIDS in China,” panel presentation at the All-China STD Conference in Shenzhen, May 23-25.
- 2011 “Best Practices in Biobanking? One size does not fit all,” PRIM&R Washington DC, December
- 2006 “ELSI Issues in *Large-Sample* Gene Discovery and Disclosure,” and “Why the Genome Institute Funds Ethics Research,” talks presented at Johns Hopkins Interdisciplinary Genetic Research Course: Medical, Public Health, Biostatistical, and Bioethical Approaches, Beijing, May 22-26
- 2005 “Therapeutic Misconception in Early Phase Gene Transfer Research,” Presented as part of panel on research ethics, Sociology of Bioethics Conference, Eastern Sociological Association, Washington DC, March 17-19.
- 2004 With Charles Lidz, Paul Appelbaum, and Alan Meisel, panel presentations on “Therapeutic Misconception: New Empirical Research.” American Society for Bioethics and Humanities Meeting, Philadelphia, October.
- 2001 Organized and moderated panel on “Nurse Rivers’ Dilemmas: Research Relationships, Ethics, and the Study Coordinator.” American Society for Bioethics and Humanities Meeting, Nashville, October.
- 1999 Organized and chaired panel on “Selling Drugs to China: Market Formation and the Struggle for the Competitive Terrain.” Annual Association for Asian Studies Meeting, Boston, March.
- 1998 Organized workshop at the China-Europe International Business School, “The Changing Nature of Chinese Antibiotics Markets, May 3, Shanghai.
- 1996 With Nancy King, organized research ethics workshops at the International Clinical Epidemiology Network meeting in Victoria Falls, Zimbabwe, January
- 1994 With Robert Levine, organized research ethics panels at the International Clinical Epidemiology Network meeting in Chiang Mai, Thailand, January
- 1994 With Scott Rozelle, organized and chaired panel on "Gender, Households, and New Economic Opportunities in Rural China." Annual Association for Asian Studies Meeting, Boston, March.
- 1992 Organized and chaired panel on "Distribution of Income and Welfare in China: Results from Recent Large-scale Surveys." Annual Association for Asian Studies Meeting, Washington, D.C., April.
- 1987 Organized and chaired panel on "Health Care Financing Under Market Socialism." Annual Association for Asian Studies Meeting, Boston, April.

Other Selected Presentations

- 2022 Eunice Okumu, Gail Henderson, Kriste Kuczynski, Nuchanart Ormsby, Carol Golin, Holly Peay, “HIV remission trials with treatment interruption of fixed duration: Trial investigators’ perceptions of strategies to mitigate HIV transmission risk,” International AIDS Society meeting, July, Montreal
- 2020 Henderson, Gail E, Holly L. Peay, and members of the Thai Remission Trials’ Decision-Making Study R01, “What does ‘HIV cure’ mean to acutely diagnosed Thai individuals invited to remission trials with ATI?” and with Stuart Rennie, “Recommendations from Thai Community Stakeholders about Protecting HIV Remission (‘Cure’) Trial Participants: Report from a Participatory Workshop,” World Congress of Bioethics virtual meeting June 19-21
- 2020 Henderson, Gail E., Holly L. Peay, and members of the Thai Remission Trials’ Decision-Making Study R01, “Is reluctance to restart ART a risk of ATI trials?”
- 2020 Henderson, Gail E, and R Jean Cadigan, “Neglected Ethical Issues in Biobanking,” presentation to the National Cancer Institute ENRICH program, April 28
- 2020 Henderson, Gail E., “Emerging Issues from the RV436 Study about Analytic Treatment Interruption,” Meeting on Acute HIV Science at US Military HIV Research Institute, Bethesda March 5, 2020
- 2019 Henderson, Gail E., “HIV Cure Research: Ethical Conundrums.” Grand Rounds at Columbia University HIV Center for Clinical and Behavioral Studies, June 13.
- 2019 Henderson, Gail E., “Ethics and decision making in ATI trials,” presentation at the Acute HIV Science Meeting, Thursday, February 28<sup>th</sup> at Henry Jackson Foundation/US Military HIV Research Program
- 2018 Henderson, Gail E., “The Ethics of treatment interruption in HIV cure trials,” and with Amy Corneli, “The convergence of socio-behavioral research and biomedical HIV prevention trials: A typology of approaches,” 4<sup>th</sup> International ASSHH Conference, Amsterdam, July 22
- 2018 Henderson, Gail E., “Ethics and HIV phylogenetics,” part of invited panel, “Harnessing information for HIV prevention,” International AIDS Society Meeting, Amsterdam, July 24
- 2017 Henderson, Gail E., “Embedding Genomics in an ELSI Study: The Case of GeneScreen,” ELSI Congress, Jackson Labs, Farmington, CT, June 5-7.
- 2017 Henderson, Gail E., “HIV Cure Trials: Why do people decide to join or decline?” Oral presentation at the 19<sup>th</sup> Bangkok International Symposium on HIV Medicine, January 18-20, Bangkok, Thailand
- 2016 Cadigan, R. J., Butterfield, R., Evans, J. P., Foreman, A. K., Goddard, K., Kuczynski, K. J., Muessig, K., Prince, A. E. R., Reuland, D., Rini, C., Roche, M. I., Van Riper, M., Skinner, D. & Henderson, G. E., “Online education and e-consent for preventive genomic screening: the

- GeneScreen pilots.” Poster presented at the American Society of Human Genetics, October, Vancouver, Canada.
- 2015 Henderson, Gail, “GeneScreen: Testing Healthy Adults for Rare Conditions,” UNC Epidemiology Student Organization Fall Speaker Series, November 4
- 2015 Henderson, Gail, “Screening healthy adults for rare, but preventable/treatable conditions: Is this Precision Medicine?” What’s The Big Idea Research Series, UNC Friday Center for Continuing Education, October 29.
- 2014 Henderson, Gail, “GeneScreen: a feasibility pilot,” presented at joint ASBH-ASHG session, San Diego, October 15-19.
- 2014 Henderson, Gail, “GeneScreen: Decisions about return of results & incidental findings in the context of public health genomics,” invited presentation at conference: Should We Offer Genomic Results to a Research Participant’s Family, Including After Death? Sponsored by the Consortium on Law and Values in Health, Environment & the Life Sciences, University of Minnesota, November 6
- 2012 Henderson, Gail, “Not a Simple Story: Contextualizing Opt-Out in U.S. Biobanks,” Economic and Social Research Council Genomics Network Conference, London April 23
- 2012 Henderson, Gail, “Ethical Issues in Biobanking,” Lecture for UNC Research Ethics Training Course, July 18
- 2012 Henderson, Gail, “Ethical Issues in STD/HIV Research,” presented at STD Training Course, Guangdong STD Center, Guangzhou, China, May 26
- 2011 Michie, Marsha, R. Jean Cadigan, Gail Henderson, Laura Beskow, “Am I a Control? Genotype-driven research recruitment and self-understandings of study participants,” Poster Presentation at PRIM&R Conference, Washington DC, December
- 2010 Henderson, Gail, “Informed Consent is Broken,” Invited speaker at 17th Annual Thomas A. Pitts Memorial Lectureship: From Laboratory To Bedside: Ethical Issues in Clinical and Translational Research, Charleston, October 29-30
- 2009 Henderson, Gail, “Gene-Environment Studies: What should we worry about?” Presentation to the UNC Reproductive Epidemiology Training Program, April 1
- 2009 Henderson, Gail, “Issues to Consider in Genetic Research Collaborations” Presentation to the National Evolutionary Synthesis Center, Meeting on Human Evolution and Adaptation to High-Altitude Hypoxia, Durham, NC, March 21
- 2009 Henderson, Gail, “Infected by HIV Stigma: Interpreting results from a population survey of City X, Guangxi Province,” Presentation to China Seminar, Stanford University, March 3

- 2008 Henderson, Gail, "HIV Testing in China: Convergence of Benefits?" Paper presented at International Symposium on Health, Equality, and Development, Shanghai, December 19-20
- 2008 Henderson, Gail, "Lots of Stores and Why that Matters" Presented for panel, "Who's Minding the Specimen Store?" Association of Bioethics and Humanities, October 24
- 2008 Henderson, Gail and Arlene Davis, "Perceptions of Direct Benefit in Gene Transfer Research: Interviews with GTR Investigators & Subjects, and Analysis of Parent-Authored Websites" ELSI Congress, March
- 2007 Henderson, Gail, "Health in China: From Mao to the Olympics, a Society in Transition," University of Wisconsin, Madison, Center for Global Health, September 17
- 2007 Henderson, Gail, "When American Medical Researchers Go Abroad: 'Your Principles Just Aren't Working on the Ground,'" University of North Carolina, Chapel Hill, Carolina Population Center Ethics Seminar, October 12
- 2006 Henderson, Gail, "Controversies in Assessing Subjects' Therapeutic Misconception in Early Phase Oncology Trials: What's the problem and can we fix it?" University of Maryland Medical School, Baltimore, March 30
- 2006 Henderson, Gail, "Equity in Health and Health Care: The Case of China," Presented at World View (International Program for Educators) March Seminar East Asia: Tradition and Transformation
- 2005 Henderson, Gail, "Is China's Rural Health Care Infrastructure Ready for AIDS?" Stanford University, January 27
- 2004 Henderson, Gail, "AIDS Research in China: Are Subjects Protected?" UNC, Carolina Asia Center, February 19.
- 2003 Henderson, Gail, "Studying Benefit in Gene Transfer Research: Data from Consent Forms and Interviews with Investigators and Subjects," Duke University, Genome, Ethics, Law and Policy Faculty Colloquium, Durham, NC, February
- 2003 Henderson, Gail and Arlene Davis, "Balancing Competing Advocacies for Patient, Subject and Study: Analysis of Interviews with Study Coordinators and Their Subjects," Presented at Association of Clinical Research Practitioners Conference, Philadelphia, April.
- 2003 Henderson, Gail, "Clinician Investigator/ Patient Subject: Can Social Science Help Us Understand the 'Dual Role'?" Presented at American Society for Bioethics and Humanities Meeting, Baltimore, October
- 2002 Henderson, Gail, "Informed Consent," and "Vulnerable Populations," presentations at Research Ethics Workshop, Beijing March 12-18, funded by the Fogarty International Center, the Ford Foundation, and the China CDC

- 1999 Henderson, Gail, "Regulatory Responses to Competition in the Pharmaceutical Industry in China in the Reform Era," Presented at the Annual Association for Asian Studies Meeting, Boston, March.
- 1998 Henderson, Gail, "The Antibiotics Wars in Shanghai," Lecture at the Division of Social Sciences and Humanities, Hong Kong University of Science and Technology, July.
- 1998 Henderson, Gail, "Globalization and Equity in the Pharmaceutical Market in China," Duke University, December.
- 1996 Henderson, Gail, Barbara Entwisle, Li Ying, Zhai Fengying, and Xu Siyuan, "The Meaning of Work: Interviews from Towns and Villages in Hubei Province, 1995" Presented at the conference, "Gender, Households, and the Boundaries of Work in China," Chapel Hill, October.
- 1995 Henderson, Gail, "Privatization of Medical Care in China," Invited Lecture by the East Asian Studies Program at the University of Washington, St. Louis.
- 1994 Entwisle, Barbara, Gail Henderson, Susan Short, Jill Bouma, and Zhai Fengying, "Gender and the Allocation of Household Labor in Rural China." Presented at the Annual Association for Asian Studies Meeting, Boston, March.
- 1993 Henderson, Gail and Scott Stroup, "The Evolution of China's Rural Health Care System: Disease Prevention Programs in a North China County." Presented at the Annual Association for Asian Studies meeting, Los Angeles, March.
- 1992 Henderson, Gail, John Akin, Li Zhiming, Ge Keyou, Ma Haijiang and Jin Shuigao, "Equity and Health Care in China: Report on an Eight-Province Survey." Presented at the Annual Association for Asian Studies Meeting, Washington, D.C., April.
- 1992 Henderson, Gail, John Akin, Li Zhiming, Jin Shuigao, Wang Jianmin and Ge Keyou, "Gender and Welfare Benefits in China: The Distribution of Health Insurance Coverage." Presented at the "Engendering China" conference. Harvard University and Wellesley College, February.
- 1992 Henderson, Gail, "Ethics and Informed Consent in Developing Nations," Carolina Population Center, Friday Seminar Series, September.
- 1991 Entwisle, Barbara, Zhai Fengying, Marck C. Hereward, Gail Henderson and Barry Popkin, "Spending Less Time, Sharing the Task: Market Work and Child Care in Eight Provinces of China." Presented at the Annual Population Association of America Meeting, March.
- 1990 Henderson, Gail, "Socioeconomic Factors and Health in the PRC." Presented at the Annual Association for Asian Studies Meeting, Chicago, April.
- 1990 Henderson, Gail, "A Case Study on US-China Collaboration." Presented as part of plenary session for "International Health Forum: Building a Common Ground." Invited conference for



US and China medical leaders, sponsored by the United States - China Educational Institute, Santa Cruz, California.

- 1989 Henderson, Gail, "Research in China in the New Environment." Presented at invited meeting of research scholars of the Committee on Scholarly Communication with the People's Republic of China, Washington DC., September.
- 1989 Henderson, Gail, "Personal Reflection on Tiananmen After a Decade of Research in China," meeting of Social Science Faculty of the UNC Health Affairs Schools, September.
- 1988 Henderson, Gail, "Impact of Economic Reforms on Health Care in China in the 1980s." Invited Speaker for Dai Lectureship Harvard School of Public Health, April.
- 1988 Henderson, Gail, "Health Development in Zouping County." Wingspread Conference on Research in Zouping County, China. Racine, Wisconsin, November.
- 1987 Henderson, Gail, "Reforms in the Management and Financing of Hospital-Based Care in China." Presented at the Annual Association for Asian Studies Meeting, San Francisco, April.
- 1986 Henderson, Gail, "Assessment of Medical Technology in the People's Republic of China." Presented at the International Conference on Technology Assessment in Health Care, Boston, January.
- 1986 Henderson, Gail, "Issues and Policies in the Modernization of Medicine and Public Health in China." Presented at conference on "China's New Technological Revolution." Harvard University, The John King Fairbank Center for East Asian Studies, Boston, May.
- 1986 Henderson, Gail, Panelist on "Equity and Access to Health Care in International Perspective," part of North Carolina Humanities Committees Program "Life At Any Cost? Ethical Dilemmas in the Changing Health Care Marketplace," Duke University, February.
- 1985 Henderson, Gail, "Health Care in China: The Transformation of the Public Health Model." Department of Sociology, Princeton University, March.
- 1984 Henderson, Gail, "Medicine and Public Health in the People's Republic of China." Lehigh University Program on Science and Technology, Bethlehem, Pennsylvania, February.
- 1983 Henderson, Gail, JoAnne Earp and Nancy Lamson, "Attitudes of a Community Sample Toward Battered Women's Use of Services: Has the Women's Movement Made a Difference?" Presented at the Annual American Sociological Association Meeting, Detroit, August-September.
- 1983 Henderson, Gail, "The Transfer of Medical Technology and Organizational Change in China." Presented at the Annual American Anthropological Association Meeting, Washington, DC, December, as part of the Wenner Gren Symposium on "Permanence and Change in Asian Health Care."

- 1982 Henderson, Gail, "The Impact of the Work Unit System on the Delivery of Medical Care in China." Yale University, Department of East Asian Studies, January.
- 1981 Henderson, Gail, "The Socialist Work Unit: Report on a Chinese Hospital." The Center for Chinese Studies, University of Michigan, Ann Arbor, October.
- 1981 Parmalee, Donna, Gail Henderson and M.S. Cohen, "Medicine Under Socialism: Some Observations on Yugoslavia and China." Presented at the Annual American Sociological Association Meeting, Toronto, Canada, August.
- 1980 Henderson, Gail, "Medical Care in China." Grand Rounds at Yale University, School of Medicine, April.

### **Teaching Responsibilities**

#### School of Medicine

- 1983-2010, 2012, 2021 Medicine and Society. Interdisciplinary, year-long, required course for first-year medical students, (approximately 60 contact hours).
- 1988-1995, 1998-2000 Course Director, Medicine and Society.
- 2010, 2012 Seminar on Research Ethics. Seminars in the Humanities and Social Sciences.
- 2013-present Seminar on Ethics and Politics of Clinical Research, Seminars in the Humanities and Social Sciences.
- 2016-2017 Intensive Integration Monthly Seminar for 3<sup>rd</sup> year Medical Students: RICE (Reflection, Inter-professional Education, Communication Skills, and Ethics).
- 1983-1990 International Health; The Rise of Technology in Medical Care. Seminars in Selective Seminars in the Social Sciences in the Social Sciences and Humanities, a required course for second-year medical students, (approximately 30 contact hours).
- 1990-2007 Health and Inequality: Sorting out the Social Causes of Illness and Differential Access to Care. Seminars in the Social Science and Humanities, (approximately 30 contact hours)
- 1993-2002 Clinical Epidemiology. A required course for second-year medical students (approximately 60 contact hours).
- 1988-1989, 2002 Lecturer in the Robert Wood Johnson Clinical Scholars program
- 1988-1990 Lecturer the Rockefeller International Clinical Epidemiology Network (INCLIN) program, both at UNC School of Medicine, (estimated 15 contact hours annually).
- 1994-1995 Designed and co-taught INCLIN course in clinically applied health social science, in two

Medical universities in China (Shanghai and Chengdu)

1985-present Independent Study Preceptor. Supervised UNC medical students on study projects in China, India, Venezuela, India, Guatemala, and other countries

UNC-CH

2005-2008 Co-instructor, campus-wide course, “Interdisciplinary Perspectives on Global Health”

1998, 2001 Sociology 169 (Medical Sociology), Department of Sociology, University of North Carolina at Chapel Hill (approximately 96 contact hours).

1993 Co-instructor, course on Chinese society, Department of Anthropology, University of North Carolina at Chapel Hill (approximately 30 contact hours).

1988-present Graduate Student Committees: MA and Ph.D. Committees in Sociology, Schools of Public Health (1 senior honors, 7 masters’ thesis and 18 doctoral dissertation committees)

2020-2022 Mentor Program, for assistant professor Megan Roberts, UNC School of Pharmacy

**Grants Funded**

07/01/2022-03/30/2027 (pending), Co-investigator, NIH, National Human Genome Research Institute, R01, “Age-based genomic screening in newborns, infants, and children: a novel paradigm in public health genomics” (PIs Jonathan Berg and Laura Milko)

07/01/2022-06/30/2024 (pending), in-kind contribution as co-investigator, R21, “Implementing and Evaluating Genetic Screening in Healthy Adults for Precision Public Health” (PI Megan Roberts)

2020-2024, Co-investigator, NIH, National Human Genome Research Institute (NHGRI), “Incidental Enhancements: Addressing a Neglected Policy Issue in Human Genome Editing,” (Principal Investigators, Eric Juengst and R. Jean Cadigan) \$777,498 annual direct

12/01/2020 – 11/30/2022 EPIICAL Social Behavioral Research Study, subcontract from RTI. The major goals of this project are to integrate a social/behavioral protocol into the EARTH pediatric HIV cohort in Southern Africa to study caregivers’ HIV experiences, ART attitudes, adherence barriers and facilitators and parental expectations from cohort membership and future clinical research.

04/2021 – 03/2023 1R34MH123328 - 01A1 (Henderson Co-PI) “Decision Support for Early Phase HIV Treatment Trials.” The purpose of this two year award is to develop a customizable decision aid (DA) for early phase HIV remission trials, addressing elements of informed choice that investigators and people living with HIV (PLHIV) find most problematic. Four aims include a survey of international HIV remission trial investigators; development and pilot testing of the DA with participants in four ACTG remission trials; a deliberative engagement with stakeholders to assess the DA; and user testing to further refine the DA.

2016-2020, Principal Investigator, NIH, National Institute of Allergy and Infectious Disease (NIAID), \$384,900 “Integrating Decision-Making Studies into HIV Cure Trials: A Real-Time Longitudinal Assessment”

The major goals of this project are 1) Explore how and why members of the SEARCH cohort in Thailand choose to join or decline participation in HIV cure trials, examine the psychosocial impacts of members' trial experiences, and assess decision satisfaction. 2) Develop, apply, and evaluate a transparent and ethical approach for sharing decision-making study findings with the clinical trial team in order to improve study processes and participants' experiences. 3) Informed by findings from Aims 1 and 2, conduct normative ethical analysis and apply deliberative methods to help improve the ethical conduct of HIV cure trials.

“Integrating Decision-Making Studies into HIV Cure Trials: A Real-Time Longitudinal Assessment,” annual direct. NCE finished 4/30/22

2007-2018, Principal Investigator, NIH, National Human Genome Research Institute (NHGRI), “Center for Genomics and Society,” \$750,000 annual direct. [Renewal awarded, 2013-2018]

2010-2011 NIH, National Human Genome Research Institute (NHGRI), Principal Investigator, Supplement to Center for Genomics and Society grant, for 2011 ELSI Congress, \$200,000

2013-2018, Co-investigator, “Unintended and Intended Implications of HIV Cure: A Social and Ethical Analysis” (Principal Investigators, Joseph Tucker and Stuart Rennie), \$546,174 annual direct.

2011-2015, Co-Principal Investigator, “NCGENES: North Carolina Clinical Genomic Evaluation by NextGen Exome Sequencing,” (Principal Investigator: Jim Evans), \$1,383,000 annual direct. (NCE 2017)

2010-2011, Principal Investigator, NIH, NHGRI, “From Specimen to Biobank: Using an Organizational Perspective to Study ELSI Issues,” \$406,000 annual direct.

2009-2011, Sub-contract Principal Investigator, NIH, NHGRI Challenge Grant, “Ethical Issues in Genotype-Driven Research Recruitment,” (Principal Investigator: Laura Beskow), \$72,278 annual direct.

2008-2013, Co-Investigator, NIH, UNC CTSA Award, (Principal Investigator: Marschall Runge) Director of Clinical Research Ethics Core until 2011, then Core Member, \$7,409,424 annual direct.

2011-2012, Principal Investigator, Supplement to UNC CTSA, “Enhancing Biobank Capacities across CTSA,” \$130,000

2007-2012, Principal Investigator, NIH, National Institute of Child Health and Development (NICHD), “Partnership for Social Science Research on HIV/AIDS in China,” \$350,000 annual direct.

2005-2016, Co-Investigator, Renewal of NIH, National Institute of Allergy and Infectious Diseases, UNC Center for AIDS Research (Principal Investigator: Ronald Swanstrom) International Core Director. \$103,000

2005-2006, Principal Investigator, UNC Lineberger Comprehensive Cancer Center Population Sciences Research Award, Subjects' Understanding of the Nature and Intent of Clinical Research in Early Phase Cancer Trials: Developing a ‘Research-Treatment’ Scale. \$11,000

2008-2012, Co-Investigator, Renewal of NIH Fogarty International Center, Bioethics Training Grant, “Strengthening Bioethics Capacity and Justice in Health” (Principal Investigator, Frieda Behets) \$236,101 annual direct.

2004-2007, Co-Principal Investigator, National Human Genome Research Institute (NHRGI), ELSI Center Planning Grant “ELSI Scale-Up: Large Sample Gene Discovery and Disclosure” (Principal Investigator: Don Bailey, Co-Principal Investigators: James Evans, Nancy King, Marcia Van Riper, Debra Skinner) \$300,000 [+1 year supplement]

2003-2007, Principal Investigator, National Human Genome Research Institute (NHGRI), Renewal of “Social Construction of Benefit in Gene Transfer Research,” \$626,486

2002-2006, Co-Principal Investigator, National Human Genome Research Institute, NIH, “Learning About Research in North Carolina” (Principal Investigator: Giselle Corbie-Smith) \$979,320 [+1 year supplement]

2002, Co-Investigator, UNC Center for Gastrointestinal Biology and Disease, “Perceptions of Risks and Benefits of Participating in Epidemiology-Genetic Studies for Blacks and Whites with and without Rectal Cancer” (CGBIB-PF73, Principal Investigator: Giselle Corbie-Smith) \$20,000.

2002-2003, Principal Investigator, Supplement grant for IRB capacity building workshops, in collaboration with the China-CDC, funded by NIH Fogarty International Center, AIDS International Training and Research Program, \$86,000.

1999-2003, Principal Investigator, National Human Genome Research Institute (NHGRI), “Social Construction of Benefit in Gene Transfer Research.” \$976,355. 4<sup>th</sup> year supplement awarded March 2002, extending grant period to 2003: \$240,385

1997-1998 Pogue Leave, Sabbatical Award from the University of North Carolina at Chapel Hill.

1997-1998 (3 months in China) The American Council of Learned Societies, Committee on Scholarly Communication with China, Research Award, “The Chinese Pharmaceutical Industry,” \$17,200.

1996-1998, Co-Investigator, The Henry Luce Foundation, Inc., “The Welfare Effects of Economic and Social Change in China.” (Principal Investigator: Barry Popkin) \$170,000.

1993-1994 UNC University Research Council research grant, to fund data analysis work from the China Health and Nutrition Survey, on the determinants of health and inequality. \$2,110.

1991-1996, Co-Investigator, National Institute of Child Health and Human Development (NICHD), "Health and Reproduction Dynamics and Social Change." 5-year Program Project P01-HD28076. (Principal Investigator: Barry Popkin) \$2,345,679.

Funded Subprojects:

1993-1995 "Community and Individual Determinants of Health," Co-Investigator (Principal Investigator: John Akin) \$200,000.

1991-1996 "Reproductive Behavior, Health and Role Dynamics," Co-Investigator (Principal Investigator: Barbara Entwisle) \$335,030.

1991-1996 "Longitudinal Data Collection and Dissemination," Co-Investigator (Principal Investigator: Barry Popkin) \$720,685.

1993-1996, Principal Investigator, National Science Foundation 3-year renewal grant. "Modeling the Health Transition." \$60,000.

1990-1992, Principal Investigator, National Science Foundation 2-year grant. "Modeling the Health Transition: An Analysis of the Consequences of Socioeconomic and Demographic Changes in China," (Co-investigators: Barry Popkin and John Akin of the UNC Carolina Population Center). This grant provided funding for travel and per diem support of Chinese collaborators in Chapel Hill, for the China Multipurpose Survey, \$40,000.

1988-1989, Co-Investigator, UNC Carolina Population Center grant for first year of data collection for the China Multipurpose Survey, a 3-wave panel study of health and nutrition (Co-investigators: Barry Popkin and John Akin of the UNC Carolina Population Center, and Ge Keyou, Zhai Fengying, and Jin Shuigao of the Chinese Academy of Preventive Medicine). \$65,000.

1987-1991, Principal Investigator, Grant from the National Academy of Sciences, Committee on Scholarly Communication with the People's Republic of China: Shandong Field Research Project. Part of a multidisciplinary team of researchers to study rural development in China, for three summers, in Zouping County \$15,000.

1986-1986, Principal Investigator, Grant from the National Program for Advanced Study and Research in China, administered by the Committee on Scholarly Communication with the People's Republic of China, under the National Academy of Sciences, for research on medical technology transfer in China \$20,000.

1984-1985 Junior Faculty Development Award, University of North Carolina, for research on medical technology transfer and the modernization of medical care in China. Interviews at four research sites in China \$3,000.

1981 North Carolina Mental Health Department, Small Grant, awarded to conduct a needs assessment survey of the women of Orange County, North Carolina. This included questionnaire development, sampling methodology, interviewer training, and statistical analysis.

### **Professional Societies**

2002-2018 American Society for Bioethics and Humanities  
1990-2000 American Public Health Association  
1978-2010 American Sociological Association  
1975-1995 Association for Asian Studies

### **Professional Service**

Consultant

5-Year Center Review Team Member, North Carolina State University, Center for Genetic Engineering and Society, February 25 and 26, 2021

External Advisor, Vanderbilt Center for Genetic Privacy and Identity in Community Settings, 2017-2021

Visitor, Treuman Katz Center for Bioethics, Seattle Children's Hospital, September 2014

Consultant to the Gates Foundation on China programs, March 2006.

Member of NIH, NHLBI, Genetics of Asthma and Hypertension Observational Study Monitoring Board, 2001-2006

Member of Protection of Human Subjects Committee, Family Health International, Research Triangle Park, North Carolina, January, 2001

The World Bank, presented seminar on the use of qualitative methods in health services research, February 8, 1996, Washington, D.C.

Rockefeller International Clinical Epidemiology Network (INCLIN) consultant. Taught first of three intensive courses in "Clinically Applied Health Social Science," at Shanghai Medical University, September 29-October 15, 1995, and at West China Medical University in Sichuan, June 15-30, 1996.

Social Science Research Council, International Pre-dissertation Fellowship Program Fellows' Conference on Research Methods, October 20-24, 1994, gave plenary session on focus group interviews, and conducted workshop on ethics and confidentiality in research.

CDC, CEHIC, Birth Defects Division, to design and implement a qualitative evaluation of the use of informed consent in a clinical trial in rural China, 1990-1993.

#### Manuscript Reviewer

AIDS and Behavior  
American Journal of Public Health  
American Association for the Advancement of Science  
American Sociological Review  
Annals of Internal Medicine  
China Quarterly  
Journal of the American Medical Association  
Journal of Chinese Affairs (Australian Journal of Chinese Affairs)  
Journal of Cross-Cultural Gerontology  
Journal of Health Policy and Planning  
PLoS One  
Social Science and Medicine  
Sexually Transmitted Diseases  
University of Michigan Press  
Yale University Press  
Harvard University Press

### Editorial Boards and Councils

Editorial Board, American Sociological Review (2001-2004)  
ELSI Editor, Genetics in Medicine (2009-2017)  
Member, Editorial Board, Annual Reviews of Genomics and Human Genetics (2015-2016)  
Member, NHGRI Advisory Council (2016-2020)

### Grant Reviewer

National Human Genome Research Institute Program on Ethical Legal and Social Implications of the Human Genome Project, Study Section member, 2006-2009  
National Institutes of Health, member of 8 Ad Hoc Study Sections, 1996-2006  
Fogarty Center, NIH, member of three study sections, chair of one 1999-2005  
Committee on Scholarly Communication with China (CSCC), National Academy of Sciences  
1993-1996, Member, CSCC Committee on Advanced Study in China  
Ford Foundation  
National Institute of Mental Health  
National Science Foundation  
Research Grants Council of Hong Kong  
Woodrow Wilson Center  
World Health Organization

### Committees and Administrative Responsibilities

#### School of Medicine

2012-2016 School of Medicine, Nominating Committee  
2011-2012 Steering Committee, LCME  
2009-present Dean's Advisory Committee  
2008-2011 Director, Ethics Core, NC Translational and Clinical Sciences Institute  
2004-present Director, International Core, Center for AIDS Research  
2000-present UNC Center for AIDS Research Developmental Awards Selection Committee  
1999-2001 Promotions Committee (Assistant to Associate)  
1999-2002 UNC Hospitals Ethics Committee, Co-chair (1999-2000)  
1999-2001 Preventive Medicine Residency Advisory Board  
1998-present Medical School Admissions Committee, Non-committee Interviewer  
1994-present International Affairs Committee of the Medical School  
1991-1993 Dean's Task Force on Women's Health  
1991-1994 Medical School Committee on Diversity  
1990-1991 Curriculum Evaluation Committee  
1990-1995 Curriculum Advisory Committee

#### UNC-CH

2016 Internal Review Committee, Howard W. Odum Institute for Research in Social Science  
2014-2015 Chair, Search Committee for Director of UNC Office of Human Research Ethics  
2014 Member, Search Committee for Chair, Department of Allied Health, School of Medicine  
2004-2010 Associate Provost for International Affairs Faculty Advisory Board  
2004-2008 Global Health Advisory Committee, Office of Global Health, School of Public Health



2001-2003 Faculty Committee on the Status of Women  
1999-2000 University Center for International Studies Graduate Travel Grants Committee  
1998-2000 Luce Scholars Selection Committee  
1996 Chancellor's Committee to Assess the University Center for International Studies  
1992-2003 Chair's Advisory Committee, East Asian Studies Curriculum