Ethical, Legal, and Social Implications of Gene-Environment Interaction Research: Workshop Resources

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Please note that this list of papers is not an exhaustive literature search of topics related to GxE and ELSI but merely a selected smaller set to introduce participants to key topics that may be explored during the workshop.

GxE Research and ELSI

Suggested Reading

1. Ackerman S, Darling K W, Lee S S, Hiatt R A, Shim J. 2017. **The ethics of translational science: imagining public benefit in gene-environment interaction research.** Engag Sci Technol Soc 3:351-374. doi: 10.17351/ests2017.152 – Detailed description of potential consequences of how GxE research is implemented.

2. Henderson G E. 2008. **Introducing social and ethical perspectives on gene-environment research.** Sociological Methods & Research 37:251-276. doi: 10.1177/0049124108323536 – General introduction of ELSI issues related to GxE research.

Other Key Papers

3. Brooks S, Goldenberg A J, Hartmann C D, Morello L, Colon-Zimmermann K. 2013. **Gene-environment interactions and health inequalities: view of underserved communities.** Journal of Community Genetics 4:425-434. doi: 10.1007/s12687-013-0143-3

4. Ackerman S, Darling K W, Hiatt R H, Lee S SJ, Shim J K. 2016. **Enacting the molecular imperative: how gene-environment interaction research links bodies and environments in the post-genomic age.** Social Science & Medicine 155:51-60. doi: 10.1016/j.socscimed.2016.03.007

5. Gruber D, Lin YS, Olden K, Sonawane B.2014. **Epigenome: biosensor of cumulative exposure to chemical and nonchemical stressors related to environmental justice.** AJPH 104:1816-1821. doi: 10.2105/AJPH.2014.302130

6. Burris H H, Vick A D. 2017. **Epigenetics and health disparities.** Curr Epidemiol Rep 4:31-37. doi: 10.1007/s40471-017-0096-x

Communicating Risks

Suggested Reading

7. Boronow K E, Brody J G, Cirillo P M, Cohn B A, Gajos K Z, Havas L,Plumb M, Susmann H P. 2021. **Outcomes from returning individual versus only study-wide biomonitoring results in an environmental exposure study using the digital exposure report-back interface (DERBI).** EHP 129. doi: 10.1289/EPH0972 – Recent article about report back of environmental exposures, what investigators should consider for report back to community, and how the community perceives results.

8. Botkin J R, Busta E R, Downey A S, Mancher M. 2018. **Returning individual research results to participants: Guidance for a new research paradigm.** National Academies of Sciences, Engineering and Medicine. doi: 10.17226/250954 – Chapter 5 gives an overview of existing research on return of results-both genetic and environmental.

Other Key Papers

9. Bruckner S, Fairman J, Garrison L, Meuschke M, Preim B, Smit N N. 2021. **An exploration of practice and preferences for the visual communication of biomedical processes.** Eurographics Workshop on Visual Computing for Biology and Medicine. doi: 10.2312/vcbm.20211339

10. Allen C G, Ayode D, Engdawork K, McBride C M, Tadele G. 2019. **Applying mental model methods to characterize understanding of gene-environment influences: the case of podoconiosis in Ethiopia.** Critical Public Health 29:84-99. DOI: 10.1080/09581596.2017.1409885

11. Hamilton J G, Waters E A. 2017. **How are multifactorial beliefs about the role of genetics and behavior in cancer causation associated with cancer risk cognitions and emotions in the U.S. population?** Journal of the Pyscological, Social and Behavioral Dimensions of Cancer 27:640-647. doi: 10.002/pon.4563

12. Goho S A. 2016. **The legal implications of report-back in household exposure studies.** EHP 124. doi: 10.1289/EHP187

Community Research

Suggested Reading

13. Anderson M Z, Begay R L, Claw K G, Fox K, Garrison N A, Tsosie K S. 2018. **A framework for enhancing ethical genomic research with Indigenous communities.** Nat Commun 9. doi: 10.1038/s41467-018-05188-3 – Framework and principles for research with indigenous communities.

14. Hoover J, Lewis J, MacKenzie D. 2017. **Mining and environmental health disparities in Native American Communities.** Current Environmental Health Reports 4:130-141. doi: 10.1007%2Fs40572-017-0140-5 – Intertwines justice and community research issues with indigenous communities.

15. Kasule M, Matshaba M, Ralefala D, Wonkam A, de Vries J. 2020. **Do solidarity and reciprocity obligations compel African researchers to feedback individual genetic results in genomics research?** BMC Medical Ethics 21. doi: 10.1186/s12910-020-00549-4 – Strong discussion on solidarity and reciprocity from the African perspective.

16. Dixon M A, Hall I, Gogana P, Henderson V, Holloway-Beth A, Kimbrough A, Levi J B, Mcdowell T, Molina Y, Moore L, Murphy A B, Murray M, Watson K, Winn R. 2019. **Engaging African American men as citizen scientists to validate a prostate cancer biomarker: work in progress.** Prog. Community Health Partnersh. 13:103-112. doi: 10.1353/cpr.2019.0043 – Emphasis on the importance of meaningful engagement in communities.

Other Key Papers

17. Beans J A, Blacksher E, Blanchard J W, Byars C, Ducheneaux G, Hiratsuka V Y, Lund J R, O'Leary M, Peercy M, Reedy J, Saunkeah B, Spicer P G, Tsosie K S, Yracheta J. 2021. **Deliberations with American Indian and Alaska Native People about the ethics of genomics: an adapted model of deliberation used with three tribal communities in the United States.** AJOB Empirical Bioethics 12:164-178. doi: 10.1080/23294515/2021/1925775

18. Corneli A, Henderson G E, Peay H L, Rennie S. 2020. **Cohorts as collections of bodies and communities of persons: insights from the SEARCH010/RV254 research cohort.** International Health 12:584-590. doi: 10.1093/inthealth.ihaa060

19. Garrison N A, Hudson M, Ballantyne L L, Garba I, Martinez A, Taualii M, Arbour L, Caron N R, Rainie S R. **Genomic research through an indigenous lens: understanding the expectations.** Annual Review of Genomics and Human Genetics 20:495-517. Doi: 10.1146/annurev-genom-083118-015434

Social and Environmental Justice

Suggested Reading

20. Brown P, Hanna B, Senier L, Shostak S. 2017. **The socio-exposome: advancing exposure science and environmental justice in the post-genomic era.** Environ Sociol. 3: 107–121. doi: 10.1080/23251042.2016.1220848 – Insights for understanding environmental justice perspectives.

21. Ferryman K, Pitcan M. 2018. **Fairness in precision medicine.** Data and Society. – Nice framework and overview of bias and considerations for ELSI issues related to big datasets in precision medicine.

22. Mulligan C J, 2021. **Systemic racism can get under our skin and into our genes.** American Journal of Physical Anthropology 175; 399-405**.** doi:10.1002/ajpa.24290 – Good overview of justice-based frameworks and introducing social and behavioral epigenetics.

Other Key Papers

23. Brooks S, Goldenberg A J, Hartmann C D, Morello L, Colon-Zimmermann K. 2013. **Gene-environment interactions and health inequalities: view of underserved communities.** Journal of Community Genetics 4:425-434. doi: 10.1007/s12687-013-0143-3

24. Doerr M, Grayson S, Yu J-H. 2020. **Developing pathways for community-led research with big data: a content analysis of stakeholder interviews.** Health Res Policy Syst. 18. doi: 10.1186/s12961-020-00589-7

Privacy and Discrimination

Suggested Reading

25. Boronow K E, Brody J G, Brown P, Perovich L J, Rudel R A, Sweeney L, Yoo J S. 2020. Privacy risks of sharing data from environmental health studies. EHP 128. doi: 10.1289/EHP4817 – Overview of privacy risks associated with environmental data.

26. Brokamp C, Halrye J, Lingren T, Ryan P, Wolfe C. 2017. **Decentralized and reproducible geocoding and characterization of community and environmental exposures for multisite studies.** Journal of the American Medical Informatics Association 25:309-314. doi: 10.1093/jamia/ocx128 – Addressing HIPAA and technical solutions to privacy concerns relevant to geospatial data.

27. Clayton E W, Halverson C M, Malin B A, Sathe N A. 2018. **A systematic literature review of individuals/ perspectives on privacy and genetic information in the United States.** PLoS One 13. doi: 10.1371/journal.pone.0204417. – Privacy and ELSI concerns related to genetic information.

Other Key Papers

28. Boronow K E, Brody J G, Brown P, Perovich L, Sweeney L, Yoo J S. 2017. **Re-identification risks in HIPAA safe harbor data: a study of data from one environmental health study.** Technol Sci. PMCID: PMC6344041

29. Zandbergen P A. 2014. **Ensuring confidentiality of geocoded health data: assessing geographic masking strategies for individual-level data.** Advances in Medicine 2014. doi: 10.1155/2014/567049

Additional Resources

GxE Research and ELSI

30. Lian J B, Spatola A, Stein G S, Stein J L, Vear L. 2021. **Epigenetics and its ethical implications.** Critical Reviews in Eukaryotic Gene Expression 31. doi: 10.1615/CritRevEukaryotGeneExpr.2020036701

31. Appelbaum P S, Sabatello M. 2017. **The precision medicine nation.** Hastings Center Report 47:19-29. doi: 10.1002/hast.736

32. Gilliland J A, Healy M A. 2012. **Quantifying the magnitude of environmental exposure misclassification when using imprecise address proxies in public health research.** Spatial and Spatio-temporal Epidemiology 3:55-67.doi: 10.1016/j.sste.2012.02.006

33. Bakermans-Kranenburg M J, van Ijzendoorn M H. **The hidden efficacy of interventions: gene x environment experiments from a differential susceptibility perspective.** Annual Review of Psychology 66:381-409. doi: 10.1146/annurev-psych-010814-015407

34. Hartz S, Levin L, Linnenbringer E, Morris J C, Moulder K, Mozersky J, Streitz M, Stock K. 2021. **Communicating 5-year risk of alzheimer's disease dementia: development and evaluation of materials that incorporate multiple genetic and biomarker research results.** J Alzheimers Dis. 79:559-572. doi: 10.3233/JAD-200993

35. Buchanan A, Meyer M N, Mozersky J, O'Dell S M, Rahm A K. 2021. **Balancing external validity and concern for psychosocial harms in translational genetic research.** Ethics & Human Research. 43:43-48. doi: 10.002/eahr.500086

36. Allard P, Landecker H, Le Goff A. 2021. **Heritable changeability: epimutation and the legacy of negative definition in epigenetic concepts.** Stud Hist Philos Sci 86:35-46. doi: 10.1016/j.shpsa.2020.12.006

Communicating Risks

37. Beck S, Dupras C, Dyke S O M, Joly Y, Maschke K, Pastien T, Rothstein M, Saulnier K M, Siebert R, Walter J, Webster A P. 2019. **Points-to-consider on return of results in epigenetic research.** Genome Med 11. doi: 10.1186/s13073-019-0646-6

38. Arnold K C, Boronow K E, Brody J G, Brown P, Gajos K Z, Havas L, Morello-Frosch R, Rudel R A, Susmann H P. 2017. **DERBI: a digital method to help reserachers offer "right-to-know" personal exposure results.** EHP 125. doi: 10.1289/EHP702

39. Baldwin K, DuBois J M, McIntosh T, Mozersky J,Parsons M, Walsh H. 2019. **Are we ready to share qualitative research data? Knowledge and preparednes among qualitative researchers, IRB members and data repository curators.** IASSIST Quarterly 43. doi: 10.29173/iq952

40. Baldwin K, DuBois J M, McIntosh T, Mozersky J,Parsons M, Walsh H. 2020. **Research participant views regarding qualitative data sharing.** Ethics Hum Res. 42:13-27. doi: 10.1002/eahr.500044

41. Allard P, DuBois M, Guaspare C, Le Goff A, Louvel S. 2019. **Epigenetics in the public sphere: interdisciplinary perspectives.** Environ Epigenet. 5. doi: 10.1093/eep/dvz019

Community Research

42. The Alaska Native Genomics Research Workshop Group, Avey J P, Beckel-Mitchener A C, Blome J, Bonham V L, Claw K, Dillard D A, Ferucci E D, Gachupin F C, Ghazarian A, Hahn M J, Hindorff L, Hiratsuka V Y, Hull S C, Jooma S, Trinidad S B, Troyer J, Walajahi H, Wilson D R, Woodbury R B. 2020. **Alaska native genomic research: perspectives from Alaska native leaders, federal staff, and biomedical researchers.** Genetics in Medicine 22:1935-1943. doi: 10.1038/s41436-020-0926-y

43. Brugge D, Missaghian M. 2006. **Protecting the Navajo people through tribal regulation of research.** Sci Eng Ethics 12:491-507. doi: 10.1007/s11948-006-0047-2

Social and Environmental Justice

44. Ferryman K. 2020. **Addressing health disparities in the food and drug administration's artificial intelligence and machine learning regulatory framework.** Journal of the American Medical Informatics Association 27:2016-2019. doi: 10.1093/jamia/ocaa133

45. Walker G. 2009. Beyond distribution and proximity: **Exploring the multiple spatialities of environmental justice.** Antipode, 41: 614-636.doi: 10.1111/j.1467-8330.2009.00691.x

46. Schlosberg D. 2004. **Reconceiving environmental justice: global movements and political theories.** Environmental Politics 13:517-530. doi: 10.1080/0964401042000229025

47. Agarwal I, Conley D, Harpak A, Mostafavi H, Pritchard J K, Przeworski M. 2020. **Variable prediction accuracy of polygenic scores within an ancestry group.** Genetics and Genomics. doi: 10.7554/eLife.48376

48. Touchstone L A. 2021. 'Hunker down' stress genes boosted in women who live in violent neighborhoods. Illinois News Bureau.

49. Cole S W, Lee M J, Greenlee A J, Mendenhall R, Rittschof C C, Robinson G E, Rodriguez-Zas S L, Turi K N.2021. **Transcriptomic analyses of black women in neighborhoods with high levels of violence.** Psychoneuroendocrinology 127. doi: 10.1016/j.psyneuen.2021.105174

50. Hourdequin M. 2021. **Environmental ethics: The state of the question.** South J Philos 59:270-308. doi: 10.1111/sjp.12436

Privacy and Discrimination

51. Beskow L M, Brelsford K M, Hammack C M. 2019. **Thoughtful leader perspectives on participants protections in precision medicine research.** Journal of Law, Medicine and Ethics 37:134-148. doi: 10.1177/1073110519840493

52. Prince A E R, Rocher M I. 2014. **Genetic information, non-discrimination, and privacy protections in genetic counseling practice.** J Genet Couns 23:891-902. doi: 10.1007/s10897-014-9743-2

53. Arbuckle L, Emam K E, Jonker E, Malin B. 2011. **Correction: a systematic review of re-identification attacks on health data.** PLoS One 10. doi: 10.1371/journal.pone.0126772

54. Carson R, Chen J T, Krieger N, Soobader M-J, Subramanian S V, Waterman P. 2002. **Zip code caveat: bias due to spatiotemporal mismatches between zip codes and US census-defined geographic areas-the public health disparities geocoding project.** AJPH 92. doi: 10.2105/AJPH.92.7.1100

55. Eman K E, Malin B, Rodgers. 2015. **Anonymising and sharing individual patient data.** BMJ 350. doi: 10.1136/bmj.h1139

56. Balk D L, Entwisle B, Gutmann M P, Rindfuss R R, VanWey L K. 2005. **Confidentiality and spatially explicit data: concerns and challenges.** National Academy of Sciences 102:15337-15342. doi: 10.1073/pnas.0507804102

57. Anderson J O, Lewis A C F, Prince A E R. 2021. **The problems with patchwork: State approaches to regulating insurer use of genetic information.** DePaul J Health Care L. 22. doi: 10.2139/ssrn.3767117