OMB No. 0925-0001/0002 (Rev. 08/12 Approved Through 8/31/2015)

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.
Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Leslie P. Francis

eRA COMMONS USER NAME (credential, e.g., agency login):

POSITION TITLE Distinguished Alfred C. Emery Professor of Law; Distinguished Professor of Philosophy

EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)

| INSTITUTION AND LOCATION | DEGREE(if applicable) | Completion DateMM/YYYY | FIELD OF STUDY |
| --- | --- | --- | --- |
| Wellesley College | B.A. | 05/1967 | Philosophy |
| University of MichiganUniversity of Utah | Ph.D.J.D. | 05/197405/1981 | PhilosophyLaw |
|  |  |  |  |

# A. Personal Statement

I hold both a Ph.D. (philosophy) and a J.D. and am a widely published and well-known scholar in the fields of privacy law and ethics, disability, and bioethics. I am President-Elect of the Pacific Division of the American Philosophical Association; immediate past co-chair of the Privacy, Confidentiality, and Security Subcommittee of the National Committee on Vital and Health Statistics and currently a member of their work group on data access and use; an elected vice-president of the International Society for Philosophy of Law and Social Philosophy (IVR); Chair-elect of the section on Law, Medicine and Health Care of the American Association of Law Schools; and a member of the Ethics Committee of the American Society for Reproductive Medicine. I am an elected fellow of the Hastings Center and a Life Member of the American Law Institute.

For the past three years, I have participated extensively in the UCEER work. My activities have included consulting on research, preliminary development of my own projects including the article listed below on patient registries, guest lecturing in the course on ethics for genetic counselors, and co-teaching (with Professor Brown) health law for non-lawyers, For this study Professor Brown and I will be responsible for Aim [x], assessing the legal and regulatory implications of the return of genetic results and incidental findings in the clinical context.

Francis, LP. 2014. Adult Consent to Continued Participation in Patient Registries, *St Louis University Journal of Health Law & Policy* 7(2): 389-405.

Francis, J. & Francis, LP. 2014. Privacy, Confidentiality, and Justice: Using Large-Scale Sets of Health Data to Improve Public Health, *Journal of Social Philosophy* 45(3): 408-431.

Stein, M., Areheart, B, Francis, LP, & Silvers, A. 2014. “Accommodating Every Body,” *University of Chicago Law Review*. 81(2): 689-757.

Francis, LP. 2010. “The Physician-Patient Relationship and a National Health Information Network, *Journal of Law, Medicine, and Ethics* 38: 36-46.

# B. Positions and Honors

## Positions and Employment

1967-70; 1972-73 Teaching Fellow, Philosophy, University of Michigan

1973-74 Assistant Professor, Philosophy, California State University, Los Angeles

1977 (summer) Visiting Assistant Professor, Philosophy, UCLA

University of Utah positions:

1977- Department of Philosophy: Assistant Professor 1977-1987; Associate Professor 1987-94; Professor 1994-; Distinguished Professor 2008-

1979- Adjunct Assistant, Associate, and full Professor, Political Science

1982- S. J. Quinney College of Law: Associate Professor 1982-87; Professor 1987-; Alfred C. Emery Chair 2000-; Distinguished Professor 2008-

1990- Adjunct Professor, Internal Medicine (Division of Medical Ethics)

2009- Adjunct Professor, Department of Family & Preventive Medicine (Division of Public Health)

2012-15 Associate Dean for Faculty Research and Development, S. J. Quinney College of Law

2012- Director, Center for Law and Biomedical Sciences, S. J. Quinney College of Law

**Other Experience and Professional Memberships**

1981-82 Law Clerk, Judge Abner Mikva, U.S. Court of Appeals, D.C. Cir.

1985- American Law Institute (elected member, 1985; life member 2010)

1996- Member, Ethics Committee, Primary Children’s Medical Center

2002-10 Member, Utah Health Data Committee; Chair, 2009-2010

2005- Member, Ethics Committee, American Society for Reproductive Medicine

2005- Member, Board of Trustees, Disability Law Center (Utah)

2009- Member, Board of Trustees, And Justice for All; chair 2013-2015

2006-2014 Member, National Committee on Vital and Health Statistics; co-chair, Privacy, Confidentiality and Security Subcommittee; currently member of the work group on data access and use

2012 Visiting Scholar, Uehiro Centre for Practical Ethics, University of Oxford

2012 Beaufort Visiting Fellow, Lady Margaret Hall, University of Oxford

2013 Distinguished Visiting Professor, San Francisco State University

## Honors

1967 Phi Beta Kappa, Wellesley College

1970-1971 Rackham Prize Fellowship, University of Michigan and Ford Foundation

1976 National Endowment for the Humanities, Summer Stipend

1981 Order of the Coif, University of Utah College of Law

2000 Rosenblatt Prize for Excellence, University of Utah

2008 Distinguished Professor of Philosophy and Law, University of Utah

2014-15 President-elect (elected), Pacific Division, American Philosophical Association

2015-16 President, Pacific Division, American Philosophical Association

2013- Fellow, Hastings Center

# C. Contribution to Science

1. I have authored or co-authored many conceptual, ethical, and legal articles on privacy and health information, including the first published paper on the ethical issues raised by syndromic surveillance and a 2007 article in the *Illinois Law Review* on interoperable electronic records that was one of the initial articles in that field (with Nicholas Terry, not listed below). I am especially interested in the responsible and just use of health information, including the role of anti-discrimination law as a protection. My work in this area has led to my being requested to testify before federal advisory committees (the National Committee on Vital and Health Statistics and the Health Information Technology Privacy Committee) and to membership on both state and national committees dealing with health data. In addition to the publications listed above, these publications are representative of my work in this area:

 Francis, LP. 2012 “When Patients Interact with EHRs: Problems of Privacy and Confidentiality,” *Houston Journal of Health Law and Policy* 12: 171-200.

 Francis, Leslie P. 20ll. “Skeletons in the Family Medical Closet,” *St. Louis University Journal of Health Law & Policy* 4(2): 371-396.

 Francis, Leslie P. You’re born with your genes?: justice and protection against discrimination in the use of genetic information. *Mt. Sinai Journal of Medicine* 77(2): 188-196, DOI: 10.1002/msj.201 (2010).

 Francis, Leslie P., “Privacy and Confidentiality: The Importance of Context,” *Monist* 91(1): 52-67 (2008).

2. I have coauthored a book and a number of articles and book chapters on ethics and infectious disease. These raise questions related to the ethics and law of genetics, including whether there are differences between horizontal and vertical transmission, whether genetic transmission is special, and whether there is a duty to warn of known exposures or disease susceptibility. They also raise questions of justice and protection from discrimination. The following additional publications are representative of my work in this area:

 Margaret P. Battin, Leslie P. Francis, Jay A. Jacobson & Charles Smith, *The Patient as Victim and Vector: Bioethics and Infectious Disease*, Oxford University Press, 2009.

Francis, Leslie P. & Francis, John G. 2013.“HIV Treatment as Prevention: Not an Argument for Continuing Criminalization of HIV Transmission,” *International Journal of Law in Context* 9(4): 520 - 534*.*

Francis, Leslie P. & Francis John G. 2012. Criminalizing Health-Related Behaviors Dangerous to Others? Disease Transmission, Transmission Facilitation, and the Importance of Trust, [Criminal Law and Philosophy](http://www.springerlink.com/content/1871-9791/) 6(1): 47-63, DOI: 10.1007/s11572-011-9136-7

Jay A. Jacobson, M.P. Battin, Jeffrey Botkin, Leslie P. Francis, James Mason, & Charles B. Smith. 2006. Vertical Transmission of Infectious Disease and Genetic Disorders, in Marcel Verweij and Angus Dawson, eds., *Public Health Ethics*, Oxford: Oxford University Press.

3. I am the author or co-author of a number of articles and book chapters on decision-making in disability, especially intellectual disability. I have developed both theoretical and practical accounts of supported decision-making that are relevant to informed consent by decision-makers who cannot function entirely on their own, including children, adolescents, and people with intellectual disabilities. These models may be especially relevant to consent of family members with genetic conditions that are associated with intellectual disabilities. In addition to the publications listed above, the following additional publications are representative:

Silvers, Anita and Francis, Leslie P. “Thinking about the good: reconfiguring metaphysics (or not) for people with cognitive disabilities.” *Metaphilosophy* 40(3-4), DOI: 10.1111/j.1467-9973.2009.01602.x (2009). Reprinted in Eva Feder Kittay & Licia Carlson, eds. *Cognitive Disability and its Challenge to Moral Philosophy* (Wiley-Blackwell 2010).

Francis, L.P., “Understanding Autonomy in Light of Intellectual Disability,” *Disability and Disadvantage*, ed. Kimberley Brownlee and Adam Cureton (Oxford University Press, 2009).

Francis, Leslie P. and Anita Silvers, “Liberalism and Independently Scripted Accounts of the Good: Meeting the Challenge of Dependent Agency,” *Social Theory and Practice* (Spring 2007): 311-334.

Silvers, Anita and Leslie P. Francis, “Justice Through Trust: Resolving the Outlier Problem in Social Contract Theory,” *Ethics* 116: 40-77 (2005).

4. I am the author or co-author of a number of articles on the law and ethics of disability discrimination. In this area, I have been especially interested in the analysis of what constitutes disability discrimination and what responses to it are appropriate. Several of my papers address these issues in the context of infants, young children, and families, the population of particular interest to this proposal. These articles are representative of my work in this area:

Silvers, Anita, and Francis, Leslie. 2013. Human Rights, Civil Rights: Prescribing Disability Discrimination Prevention in Packaging Essential Health Benefits. *Journal of Law, Medicine & Ethics* 42: 781-791.

Francis, Leslie P. & Silvers, Anita. Infanticide, Moral Status, and Moral Reasons: the importance of context, *Journal of Medical Ethics* 39(5):289-92 (2013). doi: 10.1136/medethics-2012-100767.

Silvers, Anita, and Leslie P. Francis, Playing God With Baby Doe: Quality of Life, Sanctity of Life and Unpredictable Life—Standards at Start of Life, *Georgia State Law Review* 25: 1061-1095.

Francis, Leslie P. and Anita Silvers, Debilitating Alexander v. Choate: “Meaningful Access” to Health Care for People with Disabilities, *Fordham Urban Law Journal* 35: 447-477 (2008).

5. Feminist insights and methodologies inform many discussions of role of families and relationships. My original field was philosophy of law, and I have continued to maintain an interest in this area. The theoretical idea that autonomy is relational has been especially important to my approach to informed consent, including but not limited to intellectual disability. Standpoint theory is an approach to knowledge that gives voice to disadvantaged groups in the articulation of their values and experiences. With respect to the publications listed below, I should note that the *Stanford Encyclopedia of Philosophy* is the most respected work in the field, updated regularly; selection as an author for *SEP* is a mark of one’s position in the field. The publications listed below are illustrative:

 Francis, Leslie P. & Patricia Smith. “Feminist Philosophy of Law,” Stanford Encyclopedia of Philosophy [online] (February 2013), <http://plato.stanford.edu/entries/feminism-law/>.

 Silvers, Anita, and Leslie P. Francis, “Law School Education, Disability, and Standpoint Theory,” *University of Pittsburgh Law Review* 69: 499-507 (2008).

 Francis, Leslie P. and Anita Silvers, (Mis)framing Schiavo as Discrimination against People with Disabilities, *University of Miami Law Review* 61:789-820 (2007).

 Francis, Leslie P. Employment and Intellectual Disability, 8 *Journal of Gender, Race & Justice* 299 (2004).

## More Complete List of Published Work in ResearchGate can be found at <https://www.researchgate.net/profile/Leslie_Francis>. My ssrn author page (listing primarily publications in law) is <http://papers.ssrn.com/sol3/cf_dev/AbsByAuth.cfm?per_id=511787>

# D. Research Support

## Ongoing Research Support

NSF SES-1228503-02 Francis, Leslie (PI) 09/15/2012-8/31/2015

National Science Foundation, Law & Social Sciences Program, postdoctoral fellowship to study legal issues facing adults with autism. Funding supports one Law Fellow for a two-year research project.

Role: PI and mentor

Completed Research Support

HHS FED-64S-10-7640 Francis, Leslie (PI) 04/01/2010-03/31/2011

Office of the National Coordinator for Health Information Technology, “Non-HIPAA Covered Entities.” Role: PI