## BIBLIOGRAPHY

- Ajana, Btihaj. (2010) 'Recombinant Identities: Biometrics and Narrative Bioethics'. *Journal of Bioethical Inquiry* 7 (2): 237–58.
  - (2020) 'Personal Metrics: Users' Experiences and Perceptions of Self-Tracking Practices and Data'. *Social Science Information* 59 (4): 654–78.
- Akandji-Kombe, Jean-François. (2007) Positive Obligations under the European Convention on Human Rights: A Guide to the Implementation of the European Convention on Human Rights. Human Rights Handbooks (No. 7). Strasbourg: Council of Europe.
- Alaimo, Stacy, and Susan J Hekman. (2008) 'Introduction: Emerging Models of Materiality in Feminist Theory'. In *Material Feminisms*, edited by Stacy Alaimo and Susan J Hekman. Bloomington: Indiana University Press: 1–22.
- Alpert, Sheri. (2012) 'The Specter of Commercial Neuroimaging'. *AJOB Neuroscience* 3 (4): 56–8.
- Anderson, James A, and Judy Illes. (2012) 'Neuroimaging and Mental Health: Drowning in a Sea of Acrimony'. *AJOB Neuroscience* 3 (4): 42–3.
- Anderson, James A, Ania Mizgalewicz, and Judy Illes. (2013) 'Triangulating Perspectives on Functional Neuroimaging for Disorders of Mental Health'. BMC Psychiatry 13 (1): 1–11.
- Andorno, Roberto. (2004) 'The Right Not to Know: An Autonomy Based Approach'. *Journal of Medical Ethics* 30 (5): 435–9.
- Annas, George J, and Sherman Elias. (2014) '23andMe and the FDA'. *New England Journal of Medicine* 370 (11): 985–8.
- Appleby, John. (2018) 'Should Mitochondrial Donation Be Anonymous?'. *The Journal of Medicine and Philosophy* 43 (2): 261–80.
- Appleby, John B, Lucy Blake, and Tabitha Freeman. (2012) 'Is Disclosure in the Best Interests of Children Conceived by Donation?'. In *Reproductive Donation: Practice, Policy and Bioethics*, edited by Martin Richards, Guido Pennings and John B Appleby. Cambridge: Cambridge University Press: 231–49.
- Ashida, Sato, Laura M Koehly, J Scott Roberts et al. (2010) 'The Role of Disease Perceptions and Results Sharing in Psychological Adaptation after Genetic

- Susceptibility Testing: The REVEAL Study'. European Journal of Human Genetics 18 (12): 1296–301.
- Atkins, Emily R, and Peter K Panegyres. (2011) 'The Clinical Utility of Gene Testing for Alzheimer's Disease'. *Neurology International* 3 (1): 1–3.
- Atkins, Kim. (2008) 'Narrative Identity and Practical Continuity'. In *Practical Identity and Narrative Agency*, edited by Catriona Mackenzie and Kim Atkins. New York: Routledge: 78–98.
- Barclay, Linda. (2000) 'Autonomy and the Social Self'. In *Relational Autonomy:* Feminist Perspectives on Automony, Agency, and the Social Self, edited by Catriona Mackenzie and Natalie Stoljar. Oxford: Oxford University Press: 52–71.
- Baylis, Françoise. (2012) 'The Self in Situ: A Relational Account of Personal Identity'. In *Being Relational: Reflections on Relational Theory and Health Law*, edited by Jocelyn Downie and Jennifer J Llewellyn. Vancouver: UBC Press: 109–31.
- Beeson, Diane R, Patricia K Jennings, and Wendy Kramer. (2011) 'Offspring Searching for Their Sperm Donors: How Family Type Shapes the Process'. *Human Reproduction* 26 (9): 2415–24.
- Bemelmans, Sonja, Krista Tromp, Eline Bunnik et al. (2016) 'Psychological, Behavioral and Social Effects of Disclosing Alzheimer's Disease Biomarkers to Research Participants: A Systematic Review'. *Alzheimer's* Research & Therapy 8 (1): 1–17.
- Ben-David, Shelly, and David Kealy. (2020) 'Identity in the Context of Early Psychosis: A Review of Recent Research'. *Psychosis* 12 (1): 68–78.
- Berkman, Benjamin E, Sara Chandros Hull, and Lisa Eckstein. (2014) 'The Unintended Implications of Blurring the Line between Research and Clinical Care in a Genomic Age'. *Personalized Medicine* 11 (3): 285–95.
- Besson, Samantha. (2007) 'Enforcing the Child's Right to Know Her Origins: Contrasting Approaches under the Convention on the Rights of the Child and the European Convention on Human Rights'. *International Journal of Law, Policy and the Family* 21 (2): 137–59.
- Blake, Lucy, Vasanti Jadva, and Susan Golombok. (2014) 'Parent Psychological Adjustment, Donor Conception and Disclosure: A Follow-up over 10 Years'. *Human Reproduction* 29 (11): 2487–96.
- Blauwhoff, Richard J. (2008) 'Tracing Down the Historical Development of the Legal Concept of the Right to Know One's Origins: Has "to Know or Not to Know" Ever Been the Legal Question?'. *Utrecht Law Review* 4 (2): 99–116.
- Blyth, Eric. (2012) 'Genes R Us? Making Sense of Genetic and Non-Genetic Relationships Following Anonymous Donor Insemination'. *Reproductive Biomedicine Online* 24 (7): 719–26.
- Blyth, Eric, and Lucy Frith. (2009) 'Donor-Conceived People's Access to Genetic and Biographical History: An Analysis of Provisions in Different

- Jurisdictions Permitting Disclosure of Donor Identity'. *International Journal of Law, Policy and the Family* 23 (2): 174–91.
- Borgelt, Emily L, Daniel Z Buchman, and Judy Illes. (2011) "This Is Why You've Been Suffering": Reflections of Providers on Neuroimaging in Mental Health Care'. *Journal of Bioethical Inquiry* 8 (1): 15–25.
  - (2012) 'Neuroimaging in Mental Health Care: Voices in Translation'. *Frontiers in Human Neuroscience* 6: 293–7.
- Borry, Pascal, Paul Schotsmans, and Kris Dierickx. (2004) 'What Is the Role of Empirical Research in Bioethical Reflection and Decision-Making? An Ethical Analysis'. *Medicine, Health Care and Philosophy* 7 (1): 41–53.
- Bortolotti, Lisa. (2013) 'The Relative Importance of Undesirable Truths'. *Medicine*, *Health Care and Philosophy* 16 (4): 683–90.
- Brandeis, Louis, and Samuel Warren. (1890) 'The Right to Privacy'. *Harvard Law Review* 4 (5): 193–220.
- Brandon, Priscilla. (2016) 'Body and Self: An Entangled Narrative'. *Phenomenology and the Cognitive Sciences* 15 (1): 67–83.
- British Medical Association. (2019) Access to Health Records. www.bma.org.uk /media/2821/bma-access-to-health-records-june-20.pdf.
- Bryman, Alan. (2016) *Social Research Methods*. Oxford: Oxford University Press. Buchanan, Allen. (1988) 'Advance Directives and the Personal Identity Problem'. *Philosophy & Public Affairs* 17 (4): 277–302.
- Buchman, Daniel Z, Emily L Borgelt, Louise Whiteley, and Judy Illes. (2013) 'Neurobiological Narratives: Experiences of Mood Disorder through the Lens of Neuroimaging'. *Sociology of Health & Illness* 35 (1): 66–81.
- Bulgin, Dominique, Paula Tanabe, and Coretta Jenerette. (2018) 'Stigma of Sickle Cell Disease: A Systematic Review'. *Issues in Mental Health Nursing* 39 (8): 675–86.
- Bunnik, Eline M, A Cecile JW Janssens, and Maartje HN Schermer. (2014) 'Personal Utility in Genomic Testing: Is There Such a Thing?'. *Journal of Medical Ethics* 41 (4): 322–6.
- Bunnik, Eline M, Maartje HN Schermer, and A Cecile JW Janssens. (2011) 'Personal Genome Testing: Test Characteristics to Clarify the Discourse on Ethical, Legal and Societal Issues'. *BMC Medical Ethics* 12 (1): 1–13.
- Butow, Phyllis N, Elizabeth A Lobb, Alexandra Barratt, Bettina Meiser, and Katherine M Tucker. (2003) 'Psychological Outcomes and Risk Perception after Genetic Testing and Counselling in Breast Cancer: A Systematic Review'. *Medical Journal of Australia* 178 (2): 77–81.
- Calhoun, Cheshire. (2000) 'Losing Oneself'. In *Relational Autonomy*, edited by Catriona Mackenzie and Natalie Stoljar. Oxford: Oxford University Press: 193–211.
- Callus, Thérèse. (2004) 'Tempered Hope? A Qualified Right to Know One's Genetic Origin: Odièvre v France'. *The Modern Law Review* 67 (4): 658–69.

- Camporesi, Silvia. (2019) 'When Does an Advantage Become Unfair? Empirical and Normative Concerns in Semenya's Case'. *Journal of Medical Ethics* 45 (11): 700–4.
- Carel, Havi. (2011) 'Phenomenology and Its Application in Medicine'. *Theoretical Medicine and Bioethics* 32 (1): 33–46.
  - (2016) Phenomenology of Illness. Oxford: Oxford University Press.
- Carter, Pam, Graeme T Laurie, and Mary Dixon-Woods. (2015) 'The Social Licence for Research: Why Care.Data Ran into Trouble'. *Journal of Medical Ethics* 41 (5): 404–9.
- Cassam, Quassim. (2011) 'The Embodied Self'. In *The Oxford Handbook of the Self*, edited by Shaun Gallagher. Oxford: Oxford University Press: 139–56.
- Chadwick, Ruth, Mairi Levitt, and Darren Shickle. (2014) *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility*. Cambridge: Cambridge University Press.
- Chan, Sarah, Sarah Cunningham-Burley, Giulia de Togni et al. (2020) 'Beyond Binaries: Dissolving the Empirical/Normative Divide'. *AJOB Empirical Bioethics* 11 (1): 17–19.
- Chan, Sarah W, Ed Tulloch, E Sarah Cooper et al. (2017) 'Montgomery and Informed Consent: Where Are We Now?'. *BMJ* 357–9.
- Chilibeck, Gillian, Margaret Lock, and Megha Sehdev. (2011) 'Postgenomics, Uncertain Futures, and the Familiarization of Susceptibility Genes'. *Social Science & Medicine* 72 (11): 1768–75.
- Christensen, Kurt D, Jason Karlawish, J Scott Roberts et al. (2020) 'Disclosing Genetic Risk for Alzheimer's Dementia to Individuals with Mild Cognitive Impairment'. Alzheimer's & Dementia: Translational Research & Clinical Interventions 6 (1): e12002.
- Christensen, Kurt D, J Scott Roberts, Wendy R Uhlmann, and Robert C Green. (2011) 'Changes to Perceptions of the Pros and Cons of Genetic Susceptibility Testing after APOE Genotyping for Alzheimer Disease Risk'. *Genetics in Medicine* 13 (5): 409–14.
- Christman, John, ed. (1989) *The Inner Citadel: Essays on Individual Autonomy*. New York: Oxford University Press.
  - (1991) 'Autonomy and Personal History'. *Canadian Journal of Philosophy* 21 (1): 1–24.
  - (2004) 'Narrative Unity as a Condition of Personhood'. *Metaphilosophy* 35 (5): 695–713.
  - (2015) 'Telling Our Own Stories: Narrative Selves and Oppressive Circumstance'. In *The Philosophy of Autobiography*, edited by Christopher Cowley. Chicago: University of Chicago Press: 122–40.
- Cohn, Simon. (2010) 'Picturing the Brain Inside, Revealing the Illness Outside: A Comparison of the Different Meanings Attributed to Brain Scans by Scientists and Patients'. In *Technologized Images, Technologized Bodies*,

- edited by Jeanette Edwards, Penelope Harvey, and Peter Wade. New York: Berghahn Books: 65–84.
- Cooper, Deborah, Natalie Limet, Ian McClung, and Stephen M Lawrie. (2013) 'Towards Clinically Useful Neuroimaging in Psychiatric Practice'. *The British Journal of Psychiatry* 203 (4): 242–4.
- Corsico, Paolo. (2021) "It's All About Delivery": Researchers' and Health Professionals' Views on the Moral Challenges of Accessing Neurobiological Information in the Context of Psychosis'. *BMC Medical Ethics* 22 (1): 1–15.
- Council for International Organizations of Medical Sciences. (2016) International Ethical Guidelines for Health-Related Research Involving Humans. www .cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf
- Crawshaw, Marilyn, and Ken Daniels. (2019) 'Revisiting the Use of "Counselling" as a Means of Preparing Prospective Parents to Meet the Emerging Psychosocial Needs of Families That Have Used Gamete Donation'. Families, Relationships and Societies 8 (3): 395–409.
- d'Agincourt-Canning, Lori. (2006) 'Genetic Testing for Hereditary Breast and Ovarian Cancer: Responsibility and Choice'. *Qualitative Health Research* 16 (1): 97–118.
- Daniels, Ken R., Victoria M. Grace, and Wayne R. Gillett. (2011) 'Factors Associated with Parents' Decisions to Tell Their Adult Offspring About the Offspring's Donor Conception'. *Human Reproduction* 26 (10): 2783–90.
- Davis, Dena S. (1997) 'Genetic Dilemmas and the Child's Right to an Open Future'. *Hastings Center Report* 27 (2): 7–15.
- Davis, Nicola (2020) 'Long-Term Offenders Have Different Brain Structure, Study Says'. *The Guardian*. www.theguardian.com/science/2020/feb/17/long-term-offenders-have-different-brain-structure-study-says#:~:text=Now%20resear chers%20say%20they%20have,who%20transgressed%20only%20as% 20adolescents
- de Melo-Martín, Inmaculada. (2014) 'The Ethics of Anonymous Gamete Donation: Is There a Right to Know One's Genetic Origins?'. *Hastings Center Report* 44 (2): 28–35.
  - (2016) 'How Best to Protect the Vital Interests of Donor-Conceived Individuals: Prohibiting or Mandating Anonymity in Gamete Donations?' *Reproductive Biomedicine & Society Online* 3: 100–8. https://doi.org/10.1016/j.rbms.2017.01.003.
- De Winter, Jan. (2016) Interests and Epistemic Integrity in Science: A New Framework to Assess Interest Influences in Scientific Research Processes. Lanham: Rowman & Littlefield.
- DeGrazia, David. (2005) *Human Identity and Bioethics*. Cambridge: Cambridge University Press.

- Department of Health. (2001) Donor Information Consultation: Providing Information About Gamete and Embryo Donors.
  - (2014) Mitochondrial Donation: Government Response to the Consultation on Draft Regulations to Permit the Use of New Treatment Techniques to Prevent the Transmission of a Serious Mitochondrial Disease from Mother to Child. www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/332881/Consultation\_response.pdf
- Dove, Edward S, Vicky Chico, Michael Fay et al. (2019) 'Familial Genetic Risks: How Can We Better Navigate Patient Confidentiality and Appropriate Risk Disclosure to Relatives?'. *Journal of Medical Ethics* 45 (8): 504–7.
- Dubov, Alex, and Steven Shoptawb. (2020) 'The Value and Ethics of Using Technology to Contain the Covid-19 Epidemic'. *The American Journal of Bioethics* 20 (7): W7–W11.
- Dumit, Joseph. (2003) 'Is It Me or My Brain? Depression and Neuroscientific Facts'. *Journal of Medical Humanities* 24 (1): 35–47.
  - (2004) *Picturing Personhood: Brain Scans and Biomedical Identity*. Princeton: Princeton University Press.
- Dworkin, Gerald. (1988) *The Theory and Practice of Autonomy*. Cambridge: Cambridge University Press.
- Eckert, Susan Larusse, Heather Katzen, J Scott Roberts et al. (2006) 'Recall of Disclosed Apolipoprotein E Genotype and Lifetime Risk Estimate for Alzheimer's Disease: The REVEAL Study'. *Genetics in Medicine* 8 (12): 746–51.
- Eckstein, Lisa, Jeremy R Garrett, and Benjamin E Berkman. (2014) 'A Framework for Analyzing the Ethics of Disclosing Genetic Research Findings'. *The Journal of Law, Medicine & Ethics* 42 (2): 190–207.
- Edelman, Marian Wright. (2015) 'It's Hard to Be What You Can't See'. Huffington Post, 21 August. www.huffpost.com/entry/its-hard-to-be-what-you-c\_b\_ 8022776.
- Eijkholt, Marleen. (2010) 'Sterilisation and the Birth of a Right: Effective Access to Medical Records'. *Medical Law Review* 18 (1): 96–102.
- Esplen, Mary Jane, Noreen Stuckless, Jonathan Hunter et al. (2009) 'The BRCA Self-Concept Scale: A New Instrument to Measure Self-Concept in BRCA1/2 Mutation Carriers'. *Psycho-Oncology* 18 (11): 1216–29.
- Etkin, Amit. (2019) 'A Reckoning and Research Agenda for Neuroimaging in Psychiatry'. *American Journal of Psychiatry* 176 (7): 507–11.
- Farah, Martha J. (2014) 'Brain Images, Babies, and Bathwater: Critiquing Critiques of Functional Neuroimaging'. *Hastings Center Report* 44 (s2): S19–S30.
- Farah, Martha J, and Seth J Gillihan. (2012) 'The Puzzle of Neuroimaging and Psychiatric Diagnosis: Technology and Nosology in an Evolving Discipline'. *AJOB Neuroscience* 3 (4): 31–41.

- Farrer, Lindsay A, L Adrienne Cupples, Jonathan L Haines et al. (1997) 'Effects of Age, Sex, and Ethnicity on the Association between Apolipoprotein E Genotype and Alzheimer Disease: A Meta-Analysis'. *JAMA* 278 (16): 1349–56.
- Feinberg, Joel. (1984) *Harm to Others: The Moral Limits of the Criminal Law*, vol. 1. Oxford: Oxford University Press.
- Fenech, Matthew, Nika Strukelj, and Olly Buston. (2018) *Ethical, Social, and Political Challenges of Artificial Intelligence in Health.* London: Wellcome Trust & Future Advocacy.
- Floridi, Luciano. (2019) 'Semantic Conceptions of Information'. In *Stanford Encyclopedia of Philosophy*, edited by Edward N Zalta. www.plato.stanford .edu/archives/win2019/entries/information-semantic/.
- Fortin, Jane. (2011) 'Children's Right to Know Their Origins Too Far, Too Fast?'. *Child and Family Law Quarterly* 21 (3): 336–55.
- Foster, Morris W, John J Mulvihill, and Richard R Sharp. (2009) 'Evaluating the Utility of Personal Genomic Information'. *Genetics in Medicine* 11 (8): 570–4.
- Freeman, Tabitha. (2014) 'Introduction'. In *Relatedness in Assisted Reproduction*, edited by Tabitha Freeman, Susanna Graham, Fatemeh Ebtehaj and Martin Richards. Cambridge: Cambridge University Press: 1–18.
  - (2015) 'Gamete Donation, Information Sharing and the Best Interests of the Child: An Overview of the Psychosocial Evidence'. *Monash Bioethics Review* 33 (1): 45–63.
- Freeman, Tabitha, Kate Bourne, Jadva Vasanti, and Venessa Smith. (2014) 'Making Connections: Contact between Sperm Donor Relations'. In *Relatedness in Assisted Reproduction*, edited by Tabitha Freeman, Susanna Graham, Fatemeh Ebtehaj, and Martin Richards. Cambridge: Cambridge University Press: 270–95.
- Freeman, Tabitha, and Susan Golombok. (2012) 'Donor Insemination: A Follow-up Study of Disclosure Decisions, Family Relationships and Child Adjustment at Adolescence'. *Reproductive Biomedicine Online* 25 (2): 193–203.
- Frith, Lucy, Eric Blyth, Marilyn Crawshaw, and Olga van den Akker. (2018a) 'Searching for "Relations" Using a DNA Linking Register by Adults Conceived Following Sperm Donation'. *BioSocieties* 13 (1): 170–89.
  - (2018b) 'Secrets and Disclosure in Donor Conception'. Sociology of Health & Illness 40 (1): 188–203.
- Gallagher, Shaun. (2006) *How the Body Shapes the Mind*. Wotton-under-Edge: Clarendon Press.
- Gergen, Kenneth J, and Mary M Gergen. (1988) 'Narrative and the Self as Relationship'. Advances in Experimental Social Psychology 21 (1): 17–56.
- Gibbon, Sahra. (2007) 'Charity, Breast Cancer Activism and the Iconic Figure of the BRCA Carrier'. In *Biosocialities, Genetics and the Social Sciences: Making Biologies and Identities*, edited by Sahra Gibbon and Carlos Novas. Abingdon: Routledge: 19–37.

- Gibbon, Sahra, and Carlos Novas. (2007) 'Introduction'. In *Biosocialities, Genetics* and the Social Sciences: Making Biologies and Identities, edited by Sahra Gibbon and Carlos Novas. London: Routledge: 1–18.
- Gibson, Lorna M, Thomas J Littlejohns, Ligia Adamska et al. (2017) 'Impact of Detecting Potentially Serious Incidental Findings During Multi-Modal Imaging'. Wellcome Open Research 2: 114.
- Giddens, Anthony. (1991) *Modernity and Self-Identity: Self and Society in the Late Modern Age.* Cambridge: Polity Press in association with Blackwell.
- Gilbert, Frederic. (2015) 'A Threat to Autonomy? The Intrusion of Predictive Brain Implants'. *AJOB Neuroscience* 6 (4): 4–11.
- Gilbert, Frederic, Mark Cook, Terrence O'Brien, and Judy Illes. (2019) 'Embodiment and Estrangement: Results from a First-in-Human "Intelligent BCI" Trial'. Science and Engineering Ethics 25 (1): 83–96.
- Giordano, James. (2012) 'Neuroimaging in Psychiatry: Approaching the Puzzle as a Piece of the Bigger Picture(S)'. *AJOB Neuroscience* 3 (4): 54–6.
- Glannon, Walter. (2009) 'Our Brains Are Not Us'. Bioethics 23 (6): 321-9.
- Glover, Jonathan. (1988) *I: The Philosophy and Psychology of Personal Identity*. London: Penguin.
- Golombok, Susan. (2017) 'Disclosure and Donor-Conceived Children'. *Human Reproduction* 32 (7): 1532–6.
- Golombok, Susan, Anne Brewaeys, Michele T. Giavazzi et al. (2002) 'The European Study of Assisted Reproduction Families: The Transition to Adolescence'. *Human Reproduction* 17 (3): 830–40.
- Gooding, Holly C, Erin L Linnenbringer, Jeffrey Burack et al. (2006) 'Genetic Susceptibility Testing for Alzheimer Disease: Motivation to Obtain Information and Control as Precursors to Coping with Increased Risk'. *Patient Education and Counseling* 64 (1–3): 259–67.
- Green, Robert C, and Nita A Farahany. (2014) 'Regulation: The FDA Is Overcautious on Consumer Genomics'. *Nature News* 505 (7483): 286.
- Hacking, Ian. (1995) 'The Looping Effect of Human Kinds'. In *Causal Cognition: A Multi-Disciplinary Debate*, edited by Dan Sperber, David Premack and A James Premack. New York: Oxford University Press: 351–83.
  - (1999) The Social Construction of What? Cambridge, MA: Harvard University Press.
  - (2004) 'Between Michel Foucault and Erving Goffman: Between Discourse in the Abstract and Face-to-Face Interaction'. *Economy and Society* 33 (3): 277–302.
- Hallowell, Nina. (1999) 'Doing the Right Thing: Genetic Risk and Responsibility'. *Sociology of Health & Illness* 21 (5): 597–621.
- Hallowell, Nina, Sarah Cooke, Gillian Crawford et al. (2010) 'An Investigation of Patients' Motivations for Their Participation in Genetics-Related Research'. *Journal of Medical Ethics* 36 (1): 37–45.

- Hallowell, Nina, Claire Foster, Rosalind Eeles, et al. (2004) 'Accommodating Risk: Responses to BRCA1/2 Genetic Testing of Women Who Have Had Cancer'. *Social Science & Medicine* 59 (3): 553–65.
- Hallowell, Nina, Claire Foster, Ros Eeles et al. (2003) 'Balancing Autonomy and Responsibility: The Ethics of Generating and Disclosing Genetic Information'. *Journal of Medical Ethics* 29 (2): 74–9.
- Haraway, Donna. (2006) 'A Manifesto for Cyborgs: Science, Technology, and Socialist Feminism in the 1980s'. In *International Handbook of Virtual Learning Environments*, vol. 1, edited by Joel Weiss, Jason Nolan, Jeremy Hunsinger and Peter Trifonas. New York: Springer: 117–58.
- Hardcastle, Valerie Gray. (2008) Constructing the Self. Amsterdam: John Benjamins.
- Harper, Joyce C, Debbie Kennett, and Dan Reisel. (2016) 'The End of Donor Anonymity: How Genetic Testing Is Likely to Drive Anonymous Gamete Donation out of Business'. *Human Reproduction* 31 (6): 1135–40.
- Harris, John, and Kirsty Keywood. (2001) 'Ignorance, Information and Autonomy'. *Theoretical Medicine and Bioethics* 22 (5): 415–36.
- Haslanger, Sally. (2009) 'Family, Ancestry and Self: What Is the Moral Significance of Biological Ties?'. *Adoption & Culture* 2: 91–122.
- Hauskeller, Christine. (2004) 'Genes, Genomes and Identity. Projections on Matter'. *New Genetics and Society* 23 (3): 285–99.
  - (2006) 'Human Genomics as Identity Politics.' Award Paper for Young Scholar Conference, Cornell University, 7–9 April. https://citeseerx.ist.psu.edu/view doc/download?doi=10.1.1.571.6238&rep=rep1&type=pdf.
- Hedgecoe, Adam M. (2004) 'Critical Bioethics: Beyond the Social Science Critique of Applied Ethics'. *Bioethics* 18 (2): 120–43.
- Henschke, Adam. (2010) 'Did You Just Say What I Think You Said? Talking About Genes, Identity and Information'. *Identity in the Information Society* 3 (3): 435–56.
  - (2017) Ethics in an Age of Surveillance: Personal Information and Virtual Identities. Cambridge: Cambridge University Press.
- Heshka, Jodi T, Crystal Palleschi, Heather Howley, Brenda Wilson, and Philip S Wells. (2008) 'A Systematic Review of Perceived Risks, Psychological and Behavioral Impacts of Genetic Testing'. *Genetics in Medicine* 10 (1): 19–32.
- Hesse-Biber, Sharlene, and Chen An. (2016) 'Genetic Testing and Post-Testing Decision Making among BRCA-Positive Mutation Women: A Psychosocial Approach'. *Journal of Genetic Counseling* 25 (5): 978–92.
- Hewitt, Geraldine. (2002) 'Missing Links: Identity Issues of Donor Conceived People'. *Journal of Fertility Counselling* 9: 14–19.
- Hickey, Blake Anthony, Taryn Chalmers, Phillip Newton et al. (2021) 'Smart Devices and Wearable Technologies to Detect and Monitor Mental Health Conditions and Stress: A Systematic Review'. Sensors 21 (10): 3461.

- House of Commons Science and Technology Committee. (2021) Direct-to-Consumer Genomic Testing. www.publications.parliament.uk/pa/cm5802/ cmselect/cmsctech/94/9403.htm
- Huckvale, Kit, Svetha Venkatesh, and Helen Christensen. (2019) 'Toward Clinical Digital Phenotyping: A Timely Opportunity to Consider Purpose, Quality, and Safety'. npj Digital Medicine 2 (1): 1–11.
- Human Fertilisation and Embryology Authority. (2019) HFEA Code of Practice, 9th ed. www.portal.hfea.gov.uk/media/1605/2019-12-03-code-of-practice-december-2019.pdf.
- Hurley, Ann C, Rose Harvey, J Scott Roberts et al. (2005) 'Genetic Susceptibility for Alzheimer's Disease: Why Did Adult Offspring Seek Testing?'. *American Journal of Alzheimer's Disease and Other Dementias* 20 (6): 374–81.
- Husted, Jørgen. (2014) 'Autonomy and a Right Not to Know'. In *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility*, edited by Ruth Chadwick, Mairi Levitt, and Darren Shickle. Cambridge: Cambridge University Press: 24–38.
- Ienca, Marcello, and Roberto Andorno. (2017) 'Towards New Human Rights in the Age of Neuroscience and Neurotechnology'. *Life Sciences, Society and Policy* 13 (1): 1–27.
- Ilioi, Elena, Lucy Blake, Vasanti Jadva, Gabriela Roman, and Susan Golombok. (2017) 'The Role of Age of Disclosure of Biological Origins in the Psychological Wellbeing of Adolescents Conceived by Reproductive Donation: A Longitudinal Study from Age 1 to Age 14'. *Journal of Child Psychology and Psychiatry* 58 (3): 315–24.
- Ilioi, Elena Cristiana, and Susan Golombok. (2015) 'Psychological Adjustment in Adolescents Conceived by Assisted Reproduction Techniques: A Systematic Review'. *Human Reproduction Update* 21 (1): 84–96.
- Illes, Judy, Sofia Lombera, Jarett Rosenberg, and Bruce Arnow. (2008) 'In the Mind's Eye: Provider and Patient Attitudes on Functional Brain Imaging'. *Journal of Psychiatric Research* 43 (2): 107–14.
- Jadva, Vasanti, Tabitha Freeman, Wendy Kramer, and Susan Golombok. (2009) 'The Experiences of Adolescents and Adults Conceived by Sperm Donation: Comparisons by Age of Disclosure and Family Type'. *Human Reproduction* 24 (8): 1909–19.
- Jain, Sachin H, Brian W Powers, Jared B Hawkins, and John S Brownstein. (2015) 'The Digital Phenotype'. *Nature Biotechnology* 33 (5): 462–3.
- Jenkins, Richard. (2014) Social Identity. London: Routledge.
- Johnston, Carolyn, and Jane Kaye. (2004) 'Does the UK Biobank Have a Legal Obligation to Feedback Individual Findings to Participants?'. *Medical Law Review* 12 (3): 239–67.

- Joyce, Kelly. (2005) 'Appealing Images: Magnetic Resonance Imaging and the Production of Authoritative Knowledge'. *Social Studies of Science* 35 (3): 437–62.
- Kamenova, Kalina, Amir Reshef, and Timothy Caulfield. (2014) 'Angelina Jolie's Faulty Gene: Newspaper Coverage of a Celebrity's Preventive Bilateral Mastectomy in Canada, the United States, and the United Kingdom'. *Genetics in Medicine* 16 (7): 522–8.
- Kay, Jackie. (2011) Red Dust Road: An Autobiographical Journey. London: Atlas.
- Kellmeyer, Philipp. (2017) 'Ethical and Legal Implications of the Methodological Crisis in Neuroimaging'. *Cambridge Quarterly of Healthcare Ethics* 26 (4): 530–54.
  - (2021) 'Big Brain Data: On the Responsible Use of Brain Data from Clinical and Consumer-Directed Neurotechnological Devices'. *Neuroethics* 14 (1): 83–98.
- Kenett, Jeanette, and Steve Matthews. (2008) 'Normative Agency'. In *Practical Identity and Narrative Agency*, edited by Catriona Mackenzie and Kim Atkins. New York: Routledge: 212–31.
- Kirkman, Maggie. (2003) 'Parents' Contributions to the Narrative Identity of Offspring of Donor-Assisted Conception'. Social Science & Medicine 57 (11): 2229-42.
  - (2004) 'Genetic Connection and Relationships in Narratives of Donor Assisted Conception'. *Australian Journal of Emerging Technologies and Society* 2 (1). www.hdl.handle.net/11343/33590
- Klitzman, Robert. (2009) "Am I My Genes?": Questions of Identity among Individuals Confronting Genetic Disease'. *Genetics in Medicine* 11 (12): 880–9.
- Konrad, Monica. (2005) Narrating the New Predictive Genetics: Ethics, Ethnography, and Science. Cambridge: Cambridge University Press.
- Korsgaard, Christine. (1996) *The Sources of Normativity*. Cambridge: Cambridge University Press.
  - (2009) Self-Constitution: Agency, Identity, and Integrity. Oxford: Oxford University Press.
- Kreitmair, Karola, and Mildred Cho. (2017) 'The Neuroethical Future of Wearable and Mobile Health Technology'. In *Neuroethics: Anticipating the Future*, edited by Judy Illes. Oxford: Oxford University Press: 80–107.
- Kreitmair, Karola V. (2019) 'Dimensions of Ethical Direct-to-Consumer Neurotechnologies'. *AJOB Neuroscience* 10 (4): 152–66.
- Kuhn, Thomas S. (2012) *The Structure of Scientific Revolutions*, 50th Anniversary ed. Chicago: University of Chicago Press.
- Latour, Bruno, and Steve Woolgar. (1979) *Laboratory Life: The Social Construction of Scientific Facts.* Princeton: Princeton University Press.
- Laurie, Graeme. (2002) *Genetic Privacy: A Challenge to Medico-Legal Norms*. Cambridge: Cambridge University Press.

- (2004) 'The Right Not to Know: An Autonomy Based Approach A Response to Andorno'. *Journal of Medical Ethics* 30 (5): 439–40.
- (2009) 'Personality, Privacy and Autonomy in Medical Law'. In *Rights of Personality in Scots Law: A Comparative Perspective*, edited by Niall R Whitty and Reinhard Zimmermann. Dundee: Dundee University Press: 453–83.
- (2014a) 'Privacy and the Right Not to Know: A Plea for Conceptual Clarity'. In *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility*, edited by Ruth Chadwick, Mairi Levitt and Darren Shickle. Cambridge: Cambridge University Press: 38–51.
- (2014b) 'Recognizing the Right Not to Know: Conceptual, Professional, and Legal Implications'. *The Journal of Law, Medicine & Ethics* 42 (1): 53–63.
- Laurie, Graeme, Shaun Harmon, and Edward Dove. (2019) Mason and Mccall Smith's Law and Medical Ethics, 11th ed. Oxford: Oxford University Press
- Lawrie, Stephen M, Sue Fletcher-Watson, Heather C Whalley, and Andrew M McIntosh. (2019) 'Predicting Major Mental Illness: Ethical and Practical Considerations'. *BJPsych Open* 5 (2): 1–5.
- Lawton, Georgina. (2021) Raceless: In Search of Family, Identity, and the Truth About Where I Belong. London: Sphere.
- Lebowitz, Matthew S. (2014) 'Biological Conceptualizations of Mental Disorders among Affected Individuals: A Review of Correlates and Consequences'. *Clinical Psychology: Science and Practice* 21 (1): 67–83.
- Lennon, Kathleen. (2019) 'Feminist Perspectives on the Body'. In *Stanford Encyclopedia of Philosophy*, Fall ed., edited by Edward N Zalta. www .plato.stanford.edu/archives/fall2019/entries/feminist-body/
- Lennon, Kathleen, Stella Gonzalez-Arnal, and Gill Jagger. (2012) 'Introduction' In *Embodied Selves*, edited by Stella Gonzalez-Arnal, Gill Jagger, and Kathleen Lennon. Palgrave Macmillan: 1–11.
- Levy-Lahad, Ephrat, Raphael Catane, Shlomit Eisenberg et al. (1997) 'Founder BRCA1 and BRCA2 Mutations in Ashkenazi Jews in Israel: Frequency and Differential Penetrance in Ovarian Cancer and in Breast-Ovarian Cancer Families'. *American Journal of Human Genetics* 60 (5): 1059.
- Lillehammer, Hallvard. (2014) 'Who Cares Where You Came From? Cultivating Virtues of Indifference'. In *Relatedness in Assisted Reproduction*, edited by Tabitha Freeman, Susanna Graham, Fatemeh Ebtehaj, and Martin Richards. Cambridge: Cambridge University Press: 97–112.
- Lim, Jacqueline, Mariette Macluran, Melanie Price, Barbara Bennett, and Phyllis Butow. (2004) 'Short-and Long-Term Impact of Receiving Genetic Mutation Results in Women at Increased Risk for Hereditary Breast Cancer'. *Journal of Genetic Counseling* 13 (2): 115–33.

- Lindemann, Hilde. (2016) *Holding and Letting Go: The Social Practice of Personal Identities*. Oxford: Oxford University Press.
  - (2001) Damaged Identities, Narrative Repair. Ithaca: Cornell University Press.
- Lineweaver, Tara T, Mark W Bondi, Douglas Galasko, and David P Salmon. (2014) 'Effect of Knowledge of APOE Genotype on Subjective and Objective Memory Performance in Healthy Older Adults'. *American Journal of Psychiatry* 171 (2): 201–8.
- Littlejohns, Thomas J, Jo Holliday, Lorna M Gibson et al. (2020) 'The UK Biobank Imaging Enhancement of 100,000 Participants: Rationale, Data Collection, Management and Future Directions'. *Nature Communications* 11 (1): 1–12.
- Lloyd, Genevieve. (2003) Being in Time: Selves and Narrators in Philosophy and Literature. London: Routledge.
- Lock, Margaret. (2008) 'Biosociality and Susceptibility Genes: A Cautionary Tale'. In *Biosocialities, Genetics and the Social Sciences: Making Biologies and Identities*, edited by Sahra Gibbon and Carlos Novas. London: Routledge: 56–78.
- Lock, Margaret, Sarah Cunningham-Burley, Sarah Franklin et al. (2005) 'Eclipse of the Gene and the Return of Divination 1'. *Current Anthropology* 46 (S5): S47–S70.
- Lock, Margaret, Julia Freeman, Gillian Chilibeck et al. (2007) 'Susceptibility Genes and the Question of Embodied Identity'. *Medical Anthropology Quarterly* 21 (3): 256–76.
- Lock, Margaret, Julia Freeman, Rosemary Sharples, and Stephanie Lloyd. (2006) 'When It Runs in the Family: Putting Susceptibility Genes in Perspective'. *Public Understanding of Science* 15 (3): 277–300.
- Loughlin, Michael, George Lewith, and Torkel Falkenberg. (2013) 'Science, Practice and Mythology: A Definition and Examination of the Implications of Scientism in Medicine'. *Health Care Analysis* 21 (2): 1–16.
- Lupton, Deborah. (2013) 'Quantifying the Body: Monitoring and Measuring Health in the Age of Mhealth Technologies'. *Critical Public Health* 23 (4): 393–403.
- Lynch, Henry T, Carrie Snyder, Jane F Lynch et al. (2006) 'Patient Responses to the Disclosure of BRCA Mutation Tests in Hereditary Breast-Ovarian Cancer Families'. *Cancer Genetics and Cytogenetics* 165 (2): 91–7.
- Machado, Helena, and Rafaela Granja. (2020) 'Emerging DNA Technologies and Stigmatization'. In *Forensic Genetics in the Governance of Crime*, edited by Helena Machado and Rafaela Granja. Singapore: Palgrave Pivot: 85–104.
- MacIntyre, Alasdair C. (1985) After Virtue: A Study in Moral Theory, 2nd ed. London: Duckworth.
- Mackenzie, Catriona. (2000) 'Imagining Oneself Otherwise'. In *Relational Autonomy*, edited by Catriona Mackenzie and Natalie Stoljar. Oxford: Oxford University Press: 124–51.

- (2007) 'Bare Personhood? Velleman on Selfhood'. *Philosophical Explorations* 10 (3): 263–81.
- (2008a) 'Introduction: Practical Identity and Narrative Agency'. In *Practical Identity and Narrative Agency*, edited by Catriona Mackenzie and Kim Atkins. London: Routledge: 1–28.
- (2008b) 'Imagination, Identity, and Self-Transformation'. In *Practical Identity* and Narrative Agency, edited by Kim Atkins and Catriona Mackenzie. London: Routledge: 121–45.
- (2009) 'Personal Identity, Narrative Integration, and Embodiment'. In *Embodiment and Agency*, edited by Sue Campbell, Letitia Maynell, and Susan Sherwin. Pennsylvania: Pennsylvania State University Press: 100–25.
- Mackenzie, Catriona, and Jacqui Poltera. (2010) 'Narrative Integration, Fragmented Selves, and Autonomy'. *Hypatia* 25 (1): 31–54.
  - (2011) 'Narrative Identity and Autonomy: Reply to Commentaries'. MIT Symposia on Gender, Race and Philosophy 7 (1): 1-9.
- Mackenzie, Catriona, and Jackie Leach Scully. (2007) 'Moral Imagination, Disability and Embodiment'. *Journal of Applied Philosophy* 24 (4): 335–51.
- Mackenzie, Catriona, and Natalie Stoljar. (2000) 'Introduction: Autonomy Reconfigured'. In *Relational Autonomy: Feminist Perspectives on Automony, Agency, and the Social Self*, edited by Catriona Mackenzie and Natalie Stoljar. Oxford: Oxford University Press: 3–31.
- Mackenzie, Catriona, and Mary Walker. (2015) 'Neurotechnologies, Personal Identity and the Ethics of Authenticity'. In *Handbook of Neuroethics*, edited by Jens Clausen and Neil Levy. Dordrecht: Springer: 373–92.
- Mahlstedt, Patricia P, Kathleen LaBounty, and William Thomas Kennedy. (2010) 'The Views of Adult Offspring of Sperm Donation: Essential Feedback for the Development of Ethical Guidelines within the Practice of Assisted Reproductive Technology in the United States'. *Fertility and Sterility* 93 (7): 2236–46.
- Marshall, Jill. (2014) *Human Rights Law and Personal Identity*. London: Routledge. Martin, Emily. (2010) 'Self-Making and the Brain'. *Subjectivity* 3 (4): 366–81.
- McConkie-Rosell, Allyn, and Brenda M DeVellis. (2000) 'Threat to Parental Role: A Possible Mechanism of Altered Self-Concept Related to Carrier Knowledge'. *Journal of Genetic Counseling* 9 (4): 285–302.
- McGuinness, Sheelagh, Bert-Jaap Koops, and Eva Asscher. (2010) 'Genetics, Information and Identity'. *Identity in the Information Society* 3 (3): 415–21.
- McMillan, Catriona, Edward Dove, Graeme Laurie et al. (2021) 'Beyond Categorisation: Refining the Relationship between Subjects and Objects in Health Research Regulation'. *Law, Innovation and Technology* 13 (1): 194–222.

- Mella, Sara, Barbara Muzzatti, Riccardo Dolcetti et al.(2017) 'Emotional Impact on the Results of BRCA1 and BRCA2 Genetic Test: An Observational Retrospective Study'. *Hereditary Cancer in Clinical Practice* 15 (1): 1–7.
- Merleau-Ponty, Maurice. (1962) *Phenomenology of Perception*, translated by Colin Smith. London: Routledge.
- Meyers, Diana T. (2000) 'Intersectional Identity and the Authentic Self? Opposites Attract'. In *Relational Autonomy: Feminist Perspectives on Automony, Agency, and the Social Self,* edited by Catriona Mackenzie and Natalie Stoljar. Oxford: Oxford University Press: 151–80.
- Miller, Franklin G, Michelle M Mello, and Steven Joffe. (2008) 'Incidental Findings in Human Subjects Research: What Do Investigators Owe Research Participants?'. *The Journal of Law, Medicine & Ethics* 36 (2): 271–9.
- Miller, Sarah Clark. (2013) *The Ethics of Need: Agency, Dignity, and Obligation*. London: Routledge.
- Molewijk, Bert, Anne M Stiggelbout, Wilma Otten et al. (2004) 'Scientific Contribution. Empirical Data and Moral Theory. A Plea for Integrated Empirical Ethics'. *Medicine*, *Health Care and Philosophy* 7 (1): 55–69.
- Mozersky, Jessica, and Galen Joseph. (2010) 'Case Studies in the Co-Production of Populations and Genetics: The Making of "at Risk Populations" in BRCA Genetics'. *BioSocieties* 5 (4): 415–39.
- Murdoch, Iris. (2013) The Sovereignty of Good. London: Routledge.
- National Institute for Health and Care Excellence. (2013, updated 2019)
  Guidelines: Familial Breast Cancer: Classification and Care of People at
  Risk of Familial Breast Cancer and Management of Breast Cancer and
  Related Risks in People with a Family History of Breast Cancer (Cg164).
  www.nice.org.uk/guidance/cg164
- Nazroo, James Y, Kamaldeep S Bhui, and James Rhodes. (2020) 'Where Next for Understanding Race/Ethnic Inequalities in Severe Mental Illness? Structural, Interpersonal and Institutional Racism'. Sociology of Health & Illness 42 (2): 262–76.
- Nelson, Alondra. (2008) 'Bio Science: Genetic Genealogy Testing and the Pursuit of African Ancestry'. *Social Studies of Science* 38 (5): 759–83.
  - (2016) The Social Life of DNA: Race, Reparations, and Reconciliation after the Genome. Boston: Beacon Press.
- Nelson, Jamie Lindemann. (1992) 'Genetic Narratives: Biology, Stories, and the Definition of the Family'. *Health Matrix* 2: 71.
- Niedenthal, Paula M. (2007) 'Embodying Emotion'. *Science* 316 (5827): 1002–5.

- Nordgren, Anders, and Eric T. Juengst. (2009) 'Can Genomics Tell Me Who I Am? Essentialistic Rhetoric in Direct-to-Consumer DNA Testing'. *New Genetics and Society* 28 (2): 157–72.
- Novas, Carlos, and Nikolas Rose. (2001) 'Genetic Risk and the Birth of the Somatic Individual'. *Economy and Society* 29 (4): 485–513.
- Nuffield Council on Bioethics. (2013) Donor Conception: Ethical Aspects of Information Sharing. www.nuffieldbioethics.org/publications/donor-conception
- Nussbaum, Martha Craven. (2006) Frontiers of Justice: Disability, Nationality, Species Membership. Cambridge, MA: Belknap Press.
- O'Connor, Cliodhna, and Helene Joffe. (2013) 'How Has Neuroscience Affected Lay Understandings of Personhood? A Review of the Evidence'. *Public Understanding of Science* 22 (3): 254–68.
- O'Connor, Cliodhna, Geraint Rees, and Helene Joffe. (2012) 'Neuroscience in the Public Sphere'. *Neuron* 74 (2): 220–6.
- O'Neill, Onora. (2002) Autonomy and Trust in Bioethics: Gifford Lectures. Cambridge: Cambridge University Press.
- Parens, Erik, and Paul S Appelbaum. (2019) 'On What We Have Learned and Still Need to Learn About the Psychosocial Impacts of Genetic Testing'. *Hastings Center Report* 49 (S1): S2–S9. https://doi.org/10.1002/hast.1011.
- Parfit, Derek. (1984) Reasons and Persons. Oxford: Oxford University Press.
- Parker, Michael, and Anneke M Lucassen. (2004) 'Genetic Information: A Joint Account?'. *BMJ* 329 (7458): 165–7.
- Parry, Bronwyn. (2013) 'Knowing Mycellf™: Personalized Medicine and the Economization of Prospective Knowledge About Bodily Fate'. In *Knowledge and the Economy*, edited by Peter Meusburger, Johannes Glückler, and Martina el Meskioui. Knowledge and Space (Klaus Tschira Symposia). Dordrecht: Springer: 157–71.
- Peake, Jonathan M, Graham Kerr, and John P Sullivan. (2018) 'A Critical Review of Consumer Wearables, Mobile Applications, and Equipment for Providing Biofeedback, Monitoring Stress, and Sleep in Physically Active Populations'. *Frontiers in Physiology* 9: 743.
- Pennings, Guido. (2017) 'Disclosure of Donor Conception, Age of Disclosure and the Well-Being of Donor Offspring'. *Human Reproduction* 32 (5): 969-73.
- Pickersgill, Martyn. (2011) "Promising" Therapies: Neuroscience, Clinical Practice, and the Treatment of Psychopathy'. *Sociology of Health & Illness* 33 (3): 448–64.
- Pickersgill, Martyn, Sarah Cunningham-Burley, and Paul Martin. (2011) 'Constituting Neurologic Subjects: Neuroscience, Subjectivity and the Mundane Significance of the Brain'. *Subjectivity* 4 (3): 346–65.

- Pinto-Basto, Jorge, Bárbara Guimarães, Elina Rantanen et al. (2010) 'Scope of Definitions of Genetic Testing: Evidence from a Eurogentest Survey'. *Journal of Community Genetics* 1 (1): 29–35.
- Postan, Emily. (2016) 'Defining Ourselves: Personal Bioinformation as a Tool of Narrative Self-Conception'. *Journal of Bioethical Inquiry* 13 (1): 133–51.
  - (2021) 'Narrative Devices: Neurotechnologies, Information, and Self-Constitution'. *Neuroethics* 14: 231–251.
  - (2021) 'Changing Identities in Disclosure of Research Findings'. In *The Cambridge Handbook of Health Research Regulation*, edited by Graeme Laurie, Edward Dove, Agomoni Ganguli-Mitra et al. Cambridge: Cambridge University Press.
- Rabinow, Paul. (2010) 'Artificiality and Enlightenment: From Sociobiology to Biosociality'. *Politix* 90(2): 21–46.
- Racine, Eric, Ofek Bar-Ilan, and Judy Illes. (2005) 'fMRI in the Public Eye'. *Nature Review Neuroscience* 6 (2): 159–64.
- Racine, Eric, Sarah Waldman, Jarett Rosenberg, and Judy Illes. (2010) 'Contemporary Neuroscience in the Media'. Social Science & Medicine 71 (4): 725–33.
- Raghupathi, Wullianallur, and Viju Raghupathi. (2014) 'Big Data Analytics in Healthcare: Promise and Potential'. *Health Information Science and Systems* 2 (1): 1–10.
- Ramos, Renato T. (2012) 'The Conceptual Limits of Neuroimaging in Psychiatric Diagnosis'. *AJOB Neuroscience* 3 (4): 52–3.
- Ravelingien, An, Veerle Provoost, and Guido Pennings. (2013) 'Donor-Conceived Children Looking for Their Sperm Donor: What Do They Want to Know?'. *Facts, Views & Vision in ObGyn* 5 (4): 257–64.
- Ravitsky, Vardit. (2010) "Knowing Where You Come From": The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness'. Minnesota Journal of Law, Science & Technology 11 (2): 655–84.
  - (2014) 'Autonomous Choice and the Right to Know One's Genetic Origins'. *Hastings Center Report* 44 (2): 36–7.
  - (2016) 'Donor Conception and Lack of Access to Genetic Heritage'. *American Journal of Bioethics* 16 (12): 45–6.
- Ravitsky, Vardit, and Benjamin S Wilfond. (2006) 'Disclosing Individual Genetic Results to Research Participants'. *American Journal of Bioethics* 6 (6): 8–17.
- Read, John. (2007) 'Why Promoting Biological Ideology Increases Prejudice against People Labelled "Schizophrenic". *Australian Psychologist* 42 (2): 118–28.
- Readings, Jennifer, Lucy Blake, Polly Casey et al. (2011) 'Secrecy, Disclosure and Everything in-Between: Decisions of Parents of Children Conceived by

- Donor Insemination, Egg Donation and Surrogacy'. Reproductive Biomedicine Online 22 (5): 485–95.
- Rehmann-Sutter, Christoph. (2009) 'Allowing Agency: An Ethical Model for Communicating Personal Genetic Information'. In *Disclosure Dilemmas: Ethics of Genetic Prognosis after the 'Right to Know/Not to Know' Debate*, edited by Christoph Rehmann-Sutter and Hansjakob Müller. Farnham: Ashgate: 242–73.
- Richards, Martin. (2014) 'A British History of Collaborative Reproduction and the Rise of the Genetic Connection'. In *Relatedness in Assisted Reproduction*, edited by Tabitha Freeman, Susanna Graham, Fatemeh Ebtehaj, and Martin Richards. Cambridge: Cambridge University Press: 21–43.
- Ricoeur, Paul. (1992) *Oneself as Another*, translated by Kathleen Blamey. Chicago: University of Chicago Press.
- Riessman, Catherine Kohler. (2008) *Narrative Methods for the Human Sciences*. Los Angeles: Sage.
- Roberts, J Scott. (2012) 'Genetic Testing for Risk of Alzheimer's Disease: Benefit or Burden?'. *Neurodegenerative Disease Management* 2 (2): 141–4.
- Roberts, J Scott, Kurt D Christensen, and Robert C Green. (2011) 'Using Alzheimer's Disease as a Model for Genetic Risk Disclosure: Implications for Personal Genomics'. *Clinical Genetics* 80 (5): 407–14.
- Roberts, J Scott, L Adrienne Cupples, Norman R Relkin et al. (2005) 'Genetic Risk Assessment for Adult Children of People with Alzheimer's Disease: The Risk Evaluation and Education for Alzheimer's Disease (Reveal) Study'. *Journal of Geriatric Psychiatry and Neurology* 18 (4): 250–5.
- Roberts, J Scott, and Wendy R Uhlmann. (2013) 'Genetic Susceptibility Testing for Neurodegenerative Diseases: Ethical and Practice Issues'. *Progress in Neurobiology* 110: 89–101.
- Roberts, Scott J, Susan A LaRusse, Heather Katzen et al. (2003) 'Reasons for Seeking Genetic Susceptibility Testing among First-Degree Relatives of People with Alzheimer Disease'. *Alzheimer Disease & Associated Disorders* 17 (2): 86–93.
- Roe, David, and Larry Davidson. (2005) 'Self and Narrative in Schizophrenia: Time to Author a New Story'. *Medical Humanities* 31 (2): 89–94.
- Rogers, Wendy, Catriona Mackenzie, and Susan Dodds. (2012) 'Why Bioethics Needs a Concept of Vulnerability'. *International Journal of Feminist Approaches to Bioethics* 5 (2): 11–38.
- Rose, Diana, Constantina Papoulias, James MacCabe, and Jennifer Walke. (2015) 'Service Users' and Carers' Views on Research Towards Stratified Medicine in Psychiatry: A Qualitative Study'. *BMC Research Notes* 8 (1): 1–9.
- Rose, Nikolas. (2007) Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century. Princeton: Princeton University Press.

- Rose, Nikolas S, and Joelle M Abi-Rached. (2013) Neuro: The New Brain Sciences and the Management of the Mind. Princeton: Princeton University Press.
- Roskies, Adina L. (2008) 'Neuroimaging and Inferential Distance'. *Neuroethics* 1 (1): 19–30.
- Rowbottom, Darrell P. (2019) 'Scientific Realism: What It Is, the Contemporary Debate, and New Directions'. *Synthese* 196 (2): 451–84.
- Rowley, Jennifer. (2007) 'The Wisdom Hierarchy: Representations of the DIKW Hierarchy'. *Journal of Information Science* 33 (2): 163–80.
- Royal, Charmaine D, John Novembre, Stephanie M Fullerton et al. (2010) 'Inferring Genetic Ancestry: Opportunities, Challenges, and Implications'. The American Journal of Human Genetics 86 (5): 661–73.
- The Royal Marsden NHS Foundation Trust. (2016) Patient Information: A Beginner's Guide to BRCA1 and BRCA2. www.patientinfolibrary.royalmarsden.nhs.uk /brca1brac2
- Sabatello, Maya, and Eric Juengst. (2019) 'Genomic Essentialism: Its Provenance and Trajectory as an Anticipatory Ethical Concern'. *Hastings Center Report* 49: S10–S18.
- Saini, Angela. (2019) Superior: The Return of Race Science. Boston: Beacon Press. Saks, Elyn R. (2007) The Centre Cannot Hold. London: Virago.
- Scanlon, Thomas. (1975) 'Thomson on Privacy'. *Philosophy & Public Affairs* 4 (4): 315–22.
  - (1998) What We Owe to Each Other. Cambridge: Belknap Press of Harvard University Press.
- Schechtman, Marya. (1996) *The Constitution of Selves*. Ithaca: Cornell University Press.
  - (2007) 'Stories, Lives, and Basic Survival: A Refinement and Defense of the Narrative View'. *Royal Institute of Philosophy Supplements* 60: 155-78.
  - (2012) 'Making the Truth: Self-Understanding, Self-Constitution, Neuroscience, and Narrative'. *AJOB Neuroscience* 3 (4): 75–6.
  - (2014) Staying Alive: Personal Identity, Practical Concerns, and the Unity of a Life. Oxford: Oxford University Press.
- Scheib, Joanna E, Maura Riordan, and Susan Rubin. (2003) 'Choosing Identity-Release Sperm Donors: The Parents' Perspective 13–18 Years Later'. *Human Reproduction* 18 (5): 1115–27.
- Schrijvers, Anne, Henny Bos, Floor van Rooij et al. (2019) 'Being a Donor-Child: Wishes for Parental Support, Peer Support and Counseling'. *Journal of Psychosomatic Obstetrics & Gynecology* 40 (1): 29–37.
- Scott, Susie, Lindsay Prior, Fiona Wood, and Johnathan Gray. (2005) 'Repositioning the Patient: The Implications of Being "at Risk". Social Science & Medicine 60 (8): 1869–79.

- Scully, Jackie Leach. (2008) *Disability Bioethics: Moral Bodies, Moral Difference*. Lanham: Rowman & Littlefield.
  - (2009) 'Receiving and Interpreting Information: A Joint Enterprise'. In *Disclosure Dilemmas: Ethics of Genetic Prognosis after the 'Right to Know/ Not to Know' Debate*, edited by Christoph Rehmann-Sutter and Hansjakob Müller. Farnham: Ashgate: 216–29.
  - (2017) 'A Mitochondrial Story: Mitochondrial Replacement, Identity and Narrative'. *Bioethics* 31 (1): 37–45.
- Sharon, Tamar. (2017) 'Self-Tracking for Health and the Quantified Self: Re-Articulating Autonomy, Solidarity, and Authenticity in an Age of Personalized Healthcare'. *Philosophy & Technology* 30 (1): 93–121.
- Sharon, Tamar, and Federica Lucivero. (2019) 'Introduction to the Special Theme: The Expansion of the Health Data Ecosystem Rethinking Data Ethics and Governance'. *Big Data and Society* 6 (2): 1–5.
- Shaw, Alison. (2006) 'The Contingency of the "Genetic Link" in the Construction of Kinship and Inheritance: An Anthropological Perspective'. In *Freedom and Responsibility in Reproductive Choice*, edited by John R Spencer and Antje Du Bois-Pedain. London: Hart Publishing: 73–90.
- Shildrick, Margrit. (2005) 'Introduction: Beyond the Body of Bioethics'. In *Ethics of the Body: Postconventional Challenges*, edited by Margrit Shildrick and Roxanne Mykitiuk. Cambridge, MA: MIT Press: 1–24.
- Skinner, David. (2020) 'Forensic Genetics and the Prediction of Race: What Is the Problem?'. *BioSocieties* 15 (3): 329–49.
- Skirton, Heather, Lesley Goldsmith, Leigh Jackson, and Anita O'Connor. (2012) 'Direct to Consumer Genetic Testing: A Systematic Review of Position Statements, Policies and Recommendations'. *Clinical Genetics* 82 (3): 210–18.
- Solove, Daniel J. (2002) 'Conceptualizing Privacy'. *California Law Review* 90: 1087. Somers, Margaret R. (1994) 'The Narrative Constitution of Identity: A Relational and Network Approach'. *Theory and Society* 23: 605–49.
- Staudt, Michael D, Eric Z Herring, Keming Gao, Jonathan P Miller, and Jennifer A Sweet. (2019) 'Evolution in the Treatment of Psychiatric Disorders: From Psychosurgery to Psychopharmacology to Neuromodulation'. *Frontiers in Neuroscience* 13: 1–10.
- Stewart, George. (1992) 'Interpreting the Child's Right to Identity in the UN Convention on the Rights of the Child'. *Family Law Quarterly* 26: 221–4.
- Strawson, Galen. (2008) 'Against Narrativity'. In *Real Materialism and Other Essays*, edited by Galen Strawson. Oxford: Clarendon Press: 189–208.
- Sunstein, Cass R. (1996) 'On the Expressive Function of Law'. *University of Pennsylvania Law Review* 144 (5): 2021–53.
- Tallandini, Maria Anna, Liviana Zanchettin, Giorgio Gronchi et al. (2016) 'Parental Disclosure of Assisted Reproductive Technology (Art)

- Conception to Their Children: A Systematic and Meta-Analytic Review'. *Human Reproduction* 31 (6): 1275–87.
- Taylor, Charles. (1989) Sources of the Self: The Making of the Modern Identity. Cambridge: Cambridge University Press.
  - (1992) The Ethics of Authenticity. Cambridge, MA: Harvard University Press.
- Taylor, Mark. (2012) Genetic Data and the Law: A Critical Perspective on Privacy Protection. Cambridge: Cambridge University Press.
- Thom, Robyn, and Helen M Farrell. (2019) 'Neuroimaging in Psychiatry: Potentials and Pitfalls'. *Current Psychiatry* 18 (12): 27–34.
- Topol, Eric. (2018) 'Blood, Sweat and Tears in Biotech: The Theranos Story'. *Nature* 557 (7706): 306–8.
- Turkmendag, Ilke. (2012) 'The Donor-Conceived Child's "Right to Personal Identity": The Public Debate on Donor Anonymity in the United Kingdom'. *Journal of Law and Society* 39 (1): 58–75.
- Turner, Amanda J, and Adrian Coyle. (2000) 'What Does It Mean to Be a Donor Offspring? The Identity Experiences of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy'. *Human Reproduction* 15 (9): 2041–51.
- UK National Screening Committee. (2015) Criteria for Appraising the Viability, Effectiveness and Appropriateness of a Screening Programme. www.gov.uk/ government/publications/evidence-review-criteria-national-screening-pro grammes/criteria-for-appraising-the-viability-effectiveness-and-appropriate ness-of-a-screening-programme.
- Underhill, Meghan L, Robin M Lally, Marc T Kiviniemi, Christine Murekeyisoni, and Suzanne S Dickerson. (2012) 'Living My Family's Story: Identifying the Lived Experience in Healthy Women at Risk for Hereditary Breast Cancer'. *Cancer Nursing* 35 (6): 493.
- Van Assche, Kristof, Serge Gutwirth, and Sigrid Sterckx. (2013) 'Protecting Dignitary Interests of Biobank Research Participants: Lessons from Havasupai Tribe v Arizona Board of Regents'. Law, Innovation and Technology 5 (1): 54–84.
- Van Fraassen, Bas C. (1980) *The Scientific Image*. Oxford: Oxford University Press. Vayena, Effy. (2015) 'Direct-to-Consumer Genomics on the Scales of Autonomy'. *Journal of Medical Ethics* 41 (4): 310–14.
- Vayena, Effy, Alessandro Blasimme, and I Glenn Cohen. (2018) 'Machine Learning in Medicine: Addressing Ethical Challenges'. *PLOS Medicine* 15 (11): e1002689.
- Velleman, J David. (1996) 'Self to Self'. *The Philosophical Review* 105 (1): 39–76. (2005a) 'Self as Narrator'. In *Autonomy and the Challenges to Liberalism: New Essays*, edited by John Christman and Joel Anderson. Cambridge: Cambridge University Press: 56–76.

- (2005b) 'Family History'. Philosophical Papers 34 (3): 357-78.
- (2006) Self to Self: Selected Essays. Cambridge: Cambridge University Press.
- (2008) 'The Gift of Life'. Philosophy & Public Affairs 36 (3): 245-66.
- Vodermaier, Andrea, Mary Jane Esplen, and Christine Maheu. (2010) 'Can Self-Esteem, Mastery and Perceived Stigma Predict Long-Term Adjustment in Women Carrying a BRCA1/2-Mutation? Evidence from a Multi-Center Study'. Familial Cancer 9 (3): 305–11.
- Wachbroit, Robert. (2002) 'Genetic Determinism, Genetic Reductionism, and Genetic Essentialism' In *Encyclopedia of Ethical, Legal and Policy Issues in Biotechnology*, edited by Thomas H. Murray and Maxwell J. Mehlman. New York: John Wiley: 352–6.
- Wade, Christopher H. (2019) 'What Is the Psychosocial Impact of Providing Genetic and Genomic Health Information to Individuals? An Overview of Systematic Reviews'. *Hastings Center Report* 49 (S1): S88–S96. https://doi.org/10.1002/hast.1021
- Walker, Mary Jean. (2012) 'Neuroscience, Self-Understanding, and Narrative Truth'. *AJOB Neuroscience* 3 (4): 63–74.
  - (2019) 'Two Senses of Narrative Unification'. *Philosophical Explorations* 22 (1): 78–93.
- Walker, Mary Jean, and Wendy A Rogers. (2017) 'Diagnosis, Narrative Identity, and Asymptomatic Disease'. *Theoretical Medicine and Bioethics* 38 (4): 307–21.
- Weiner, Kate, Paul Martin, Martin Richards, and Richard Tutton. (2017) 'Have We Seen the Geneticisation of Society? Expectations and Evidence'. *Sociology of Health & Illness* 39 (7): 989–1004.
- Widdows, Heather. (2013) *The Connected Self: The Ethics and Governance of the Genetic Individual.* Cambridge: Cambridge University Press.
- Widmer, Pierre. (1994) *Human Rights Issues in Research on Medical Genetics*. Strasbourg: Council of Europe.
- Wilson, Margaret. (2002) 'Six Views of Embodied Cognition'. *Psychonomic Bulletin & Review* 9 (4): 625–36.
- Wilson, Sarah. (1997) 'Identity, Genealogy and the Social Family: The Case of Donor Insemination'. *International Journal of Law, Policy and the Family* 11 (2): 270–97.
- Wisdom, Jennifer P., Kevin Bruce, Goal Auzeen Saedi, Teresa Weis, and Carla A Green. (2008) "Stealing Me from Myself": Identity and Recovery in Personal Accounts of Mental Illness'. *Australian and New Zealand Journal of Psychiatry* 42 (6): 489–95.
- Witz, Anne. (2000) 'Whose Body Matters? Feminist Sociology and the Corporeal Turn in Sociology and Feminism'. *Body & Society* 6 (2): 1–24.
- Wolf, Susan M, Frances P Lawrenz, Charles A Nelson et al. (2008) 'Managing Incidental Findings in Human Subjects Research: Analysis and Recommendations'. *The Journal of Law, Medicine & Ethics* 36 (2): 219–48.

- World Health Organization. (2021) Global Strategy on Digital Health 2020–2025. www.who.int/docs/default-source/documents/gs4dhdaa2a9f352b0445 bafbc79ca799dce4d.pdf
- Xafis, Vicki, G Owen Schaefer, Markus K Labude et al. (2019) 'An Ethics Framework for Big Data in Health and Research'. *Asian Bioethics Review* 11 (3): 227–54.
- Young, Iris Marion. (2005) 'Throwing Like a Girl: A Phenomenology of Feminine Body Comportment Motility and Spatiality'. In *On Female Body Experience:* 'Throwing Like a Girl' and Other Essays. Oxford: Oxford University Press: 27–45
- Young, Robert. (1982) 'The Value of Autonomy'. *The Philosophical Quarterly* 32 (126): 35–44.
- Zadeh, Sophie, Elena Ilioi, Vasanti Jadva, and Susan Golombok. (2018) 'The Perspectives of Adolescents Conceived Using Surrogacy, Egg or Sperm Donation'. *Human Reproduction* 33 (6): 1099–106.
- Zeiler, Kristin. (2009) 'Symposium on Genetics, Identity and Ethics'. *New Genetics and Society* 28 (2): 153–6.