Bio

Meghan Halley, PhD, MPH, is a Senior Research Scholar in the Center for Biomedical Ethics (SCBE) at Stanford University. She completed her doctorate in medical anthropology from Case Western Reserve University in 2012, and additional training in health services research at the Palo Alto Medical Foundation Research Institute from 2012 through 2016. After a hiatus from research to care for her second child, who was born with a rare genetic condition that remains undiagnosed, Dr. Halley joined SCBE in 2020. Her current research focuses at the intersection of the ethics and economics of new genomic technologies. Her current projects include: 1) examining ethical issues related to sustainability and governance of patient data and relationships when large clinical genomic studies transition to new models of funding; 2) exploring how diverse stakeholders perceive value in the use of genome sequencing for diagnosis of rare diseases; and 3) developing new measures for assessing patient-centered outcomes in pediatric rare diseases. She is also a member of the patient and family advisory group of the Undiagnosed Diseases Network, where her son is a current participant.

INSTITUTE AFFILIATIONS

• Member, Maternal & Child Health Research Institute (MCHRI)

SERVICE, VOLUNTEER, AND COMMUNITY WORK

• Co-Chair, Patient Education and Empowerment Resource (January 1, 2021)

Publications

PUBLICATIONS

• A call for an integrated approach to improve efficiency, equity and sustainability in rare disease research in the United States. Nature genetics
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• Perceived utility and disutility of genomic sequencing for pediatric patients: Perspectives from parents with diverse sociodemographic characteristics. American journal of medical genetics, Part A
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• From "Ought" to "Is": Surfacing Values in Patient and Family Advocacy in Rare Diseases. The American journal of bioethics : AJOB
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• Opportunities and pitfalls of social media research in rare genetic diseases: a systematic review. *Genetics in medicine: official journal of the American College of Medical Genetics*
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• Barriers and facilitators to mobile health and active surveillance use among older adults with skin disease. *Health expectations: an international journal of public participation in health care and health policy*
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• A Typology of Existing Machine Learning-Based Predictive Analytic Tools Focused on Reducing Costs and Improving Quality in Health Care: Systematic Search and Content Analysis. *Journal of medical Internet research*
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• "Doctors can read about it, they can know about it, but they've never lived with it": How parents use social media throughout the diagnostic odyssey. *Journal of genetic counseling*
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• Age-Related Differences in Experiences with Social Distancing at the Onset of the COVID-19 Pandemic: A Computational and Content Analytic Investigation of Natural Language. *JMIR human factors*
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• Use of social media in rare and undiagnosed disease research: a systematic review
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• "It seems like COVID-19 now is the only disease present on Earth": living with a rare or undiagnosed disease during the COVID-19 pandemic. *Genetics in medicine: official journal of the American College of Medical Genetics*
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• The Intersection of Work and Home Challenges Faced by Physician Mothers During the Coronavirus Disease 2019 Pandemic: A Mixed-Methods Analysis. *Journal of women's health (2002)*
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• Anxiety Levels Among Physician Mothers During the COVID-19 Pandemic. *The American journal of psychiatry*
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  Halley, M. C., Mangurian, C. n.
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• When All You Have Is Quality of Life - Making Medical Decisions in the Face of Uncertainty. *The New England journal of medicine*
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• Barriers and Facilitators to Real-world Implementation of the Diabetes Prevention Program in Large Healthcare Systems: Lifestyle Coach Perspectives. *Journal of general internal medicine*
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• Differing views regarding diet and physical activity: adolescents versus parents' perspectives. *BMC pediatrics*
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• Association between financial links to indoor tanning industry and conclusions of published studies on indoor tanning: systematic review. *BMJ (Clinical research ed.)*
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