Adoptees’ interest in genetic testing as a mechanism to fill gaps in family health history is clear. In addition to focus groups, surveys, and published narratives that clearly state significant interest, large scale studies of Direct-to-Consumer (DTC) genetic testing clients demonstrate that interest in inherited disease information is the leading motivator for seeking genetic test results, and that this purpose is cited as significantly more influential among adoptees than it is among non-adopted clients. Despite this interest, tremendous skepticism exists concerning genetic testing of adoptees. To address these concerns, a multidisciplinary team of bioethicists, geneticists, psychologists specializing in adoption studies, and genetic counselors has engaged the adoption community, and the broader community at large, to make clearer what limits should be placed on genetic testing in this community, the role such testing might play in the lives of adopted persons, and the need for study of looming issues that need sustained analysis.

In order to avoid similar unintended consequences for adoptees requires sustained, multifaceted engagement is necessary to identify important values and concerns that adoptees have about the potential use and misuse of genetic testing. Within the adoption community, our focus group research (Strong et al, 2017) has identified concerns expressed by adoptees that their interest in genetic testing not be exploited to further scientific aims that may not be in the interest of adoptees. It is our belief that proper engagement of this community can mitigate these concerns and optimize benefit for this community.

In addition to important interaction with the adoption community through avenues like the Rudd Family Foundation Annual “New Worlds in Adoption” Conference at the University of Massachusetts Amherst (at which we have presented on several occasions), our engagement of the adoption community has been disseminated through several publications in the academic literature. The first was a perspective piece published in Pediatrics (2015) that outlined an adoptive parental perspective and the complex motivations of adoptive parents in seeking genetic testing of their adopted children. Of particular emphasis is the need to separate considerations relating to the child’s welfare from considerations related to addressing insecurities felt by adoptive parents due to their inability to provide family health history information.

The second was a publication in Adoption and Fostering (Strong et al 2017) that explored the
findings of a qualitative study of adult adoptee attitudes toward genetic testing and health. A series of four focus groups consisting of ~20 adult adoptees (both domestic and international) explored hopes and concerns about genetic testing. Desires for genetic testing centered most commonly on adoptees’ wish to have this information to pass to their own children, and to maintain control over their own adoption journey (for example, by making reunion “optional” or pursued within one’s own time schedule, rather than necessitated by a desire or need for family health history). Concerns most commonly centered on testers’ motivations and concerns about potential secondary uses of genetic information or materials.

The third engagement publication consisted of an analysis of trust and its relationship to research projects meant to develop genetic testing protocols for adopted persons, published in the Journal of Community Engagement and Scholarship (Zusevics et al, 2018). Based on focus group discussions, this paper emphasized the need to include members of the adoption community as active members of the research team in order to address concerns, and ensure that the unique interests of adopted persons are not neglected or unintentionally overlooked. We are proud that our own research team includes adoptees, adoptive parents, and researchers closely engaged in adoption studies from a variety of perspectives.

Full engagement involves education of pertinent issues within both the adoption community and the broader community at large. In this context, our engagement efforts have included participation in media interviews and as an informational resource for media stories surrounding adoptees and genetic testing. These efforts can be divided into media stories in the print media, and in non-print forms of media (primarily radio and podcast interviews).

Under the category of print media, a New York Magazine article (http://mymag.com/sciencefus/2017/01/how-adoptees-fill-gaps-in-their-family-medical-history.html) looked closely at the challenges adoptees face because of lack of access to family health history, and featured project investigators prominently. A similar story appeared in the Huntsville Times (Alabama) (https://www.al.com/news/huntsville/index.ssf/2018/06/alabama_dna_expert_warns_against.html) and in Genome Magazine (Winter 2015), Sonya Collins Reporting, each emphasizing the potential role of genomic medicine in addressing these challenges. Potential concerns about how genetic testing for health might be used for other purposes were explored in stories by STAT news service (https://www.statnews.com/2018/06/21/congress-genetic-testing-companies-privacy-policies/), Business Insider, the French Financial newspaper Les Echo, and the Spokane, WA Inlander News. Each of these stories liberally quoted project team members.

Under the category of non-print media, Project Principal Investigator Thomas May was featured on Alabama Public Radio in a discussion of how genetic technologies might (and in some cases might not) provide valuable health information to adoptees (http://wlrh.org/News/adoptees-dias-cover-more-genomics-sequencing), and a 20-minute segment of the syndicated radio show “Your Health” (https://yourhealthradio.org/2017/09/22/the-challenge-of-not-having-relatives-health-histories/) examined in detail the ways adoptees have sought family health history information through genetic testing. A Podcast for the journal Genetics in Medicine (the official journal of the American College of Medical Genetics and Genomics) featured Dr. May in a discussion of the potential and limitations of genetic testing for this purpose in adopted persons (http://www.nature.com/multimedia/podcast/gim/gim_07012015.mp3).
Perhaps the most important engagement activity we have conducted is a special symposium issue of the journal *Narrative Inquiry in Bioethics* (May, Lee and Evans, 2018) that we have guest edited, which features personal stories of the challenges faced by adoptees within the U.S. healthcare system, due to lack of family health history information that might be mitigated through the use of genetic technologies to provide this type of information. In addition to 12 personal narratives by adopted persons, the issue also features a narrative by adoptive parents on behalf of an adopted person who died of an inherited disease that might have been caught earlier and more effectively treated if family health history information (or its genetic equivalent) had been available, and four commentaries by genetic researchers, geneticists, physicians, and adoption psychologist Harold Grotevant discussing these narratives in context.

It is our hope that these engagement activities will provide a resource for adoptees, adoptive parents, and to physicians who care for individuals within the adoption community to optimize healthcare for this community. In addition, it is our hope to raise awareness of the issues we have explored so as to motivate effective research into effective testing platforms for inherited disease in those who lack family health history.

**Implications for the Future of Adoption: Research**

- There is a need for trusted information sources concerning reliability and application of genetic test results for adopted persons.
- Effects of genetic testing on the behavior and emotional well-being of adoptees is required.
- Continued engagement of the adoption community is essential to mitigate risk and optimize benefits of genetic testing for this community.

**Implications for the Future of Adoption: Practice**

- Both adoptees and adoptive parents will likely continue to seek genetic testing as a way to fill gaps in heritage information.
- The limitations of genetic information must be recognized and associated risks fully appreciated before testing is undertaken.

**Implications for the Future of Adoption: Policy**

- There is a need to regulate use of genetic testing on adopted persons:
  - stigma and the potential for creation of the “un-adoptable child”
  - rights and interests in not knowing some information must be incorporated into policies concerning when inherited disease testing is undertaken (e.g. childhood, adolescence, or adulthood?)
A full list of our Research Team’s output on this project is included below:

Project Publications/References


Professional Conference Presentations for this Project


American Public Health Association, Annual Meeting, “Genomics as a Source of Family Health History Information”, Chicago, IL (Nov. 2015) (Post-Doctoral fellow Kaija Zusevics was awarded “best new researcher” by the APHA genomics forum for her work on this project)


Medical College of Wisconsin, Program in Genomics and Ethics Annual Symposium, “Using Genomic Technologies to Fill Gaps in Family Health History Information for Adoptees,” Milwaukee, WI (2016)


NHGRI West Coast Regional CEER (Centers for Excellence in ELSI Research) Meeting, “The Development of an Adoption Genomics ELSI Project” Seattle, WA (Feb., 2015)

American College of Medical Genetics and Genomics Annual Meeting, “Focus Group Attitudes and Opinions About the Potential Use of Genomic Sequencing as a Substitute for Biological Family History for Adult Adoptees,” (Poster), Nashville, TN (March 2014)

Media Attention to this Project

Print: New York Magazine, Business Insider, Genome Magazine, STAT news service, Les Echo (French Newspaper), the Spokane, WA Inlander News, the Huntsville Times (AL.com)

Radio: featured on Alabama Public Radio; a 20-minute segment of the syndicated radio show “Your Health;” and the official Podcast of Genetics in Medicine
Authors

Thomas May

Thomas May, Ph.D., is the Floyd and Judy Rogers Endowed Professor in the Elson S. Floyd College of Medicine at Washington State University; he is also a Research Faculty Investigator at the HudsonAlpha Institute for Biotechnology. He has spent most of his career working on issues at the intersection of medicine, public health, and moral/political philosophy, with a special interest in issues related to Autonomy and Healthcare. These issues most commonly pertain to rights of informed consent, other regarding harms, and the scope and limits of professional obligations/rights of conscience. Current interests surround issues of identity and autonomy in genomic medicine: because genomics is so closely tied to identity by many, the influence of genomic information on autonomy is significant. In this regard, he has been most interested in issues of how autonomy relates to self-identity and well-being; the role of autonomy in deciding how rights to genomic information, as well as rights to genomic ignorance, should be framed; and the assessment of risk within the context of other-regarding implications that emerge from genomic information.