



# Narrative Inquiry in Bioethics

A Journal of Qualitative Research

## Call for Stories

### Healthcare Challenges Faced by Adopted Persons Lacking Family Health History Information

*Symposium Editors Thomas May, PhD, Richard Lee, PhD and James P. Evans, MD, PhD*

*Narrative Inquiry in Bioethics* will publish a collection of personal stories from adopted individuals about challenges they face in seeking healthcare while lacking family health history information from genetic relatives. We will approach the experiences of adopted persons in this context from a variety of perspectives. The symposium editors' past work has identified diverse concerns of adopted persons seeking healthcare such as embarrassment about lacking a family health history, delayed symptom identification, and over-testing, as well as the hope that genetic testing might alleviate these negative experiences. Toward this end, we are collecting stories to document and explore the types of real scenarios and interactions that need to be understood or addressed.

**We seek stories from adopted individuals who have first-hand experience engaging health services where better access to family health history would have been helpful.**

We want true, personal stories in a form that is interesting and easy to read. **Please share this invitation and guide sheet with appropriate individuals.**

In writing your story, please consider these questions:

- How have your healthcare providers reacted to your not having family health history information?
- Do you believe better access to family health history would help guide your healthcare, and if so, how? E.g., have symptoms of an inherited condition been missed or misinterpreted because you did not have a family history to provide context for interpreting these symptoms?
- Have you ever been subjected to unnecessary testing or screening because you did not have family health history to help assess risk for inherited disease?
- Have you considered, or undertaken genetic testing, either in a medical context or direct-to-consumer context, related to your lack of family health history? If so, have you found this effective in “filling in” missing family health history?
- Do you have any advice based on your experience that you would offer to other adopted persons or to healthcare providers?

You do not need to address each of these questions—write on the issues that you think are most important to share with others. **If you are not a writer, tell your story in your own words and our editorial staff will help you.**

If you are interested in submitting a story, we ask you to **first submit a 300-word proposal**—a short description of the story you want to tell. **Inquiries or proposals should be sent to the editorial office via email: [narrativebioethics@gmail.com](mailto:narrativebioethics@gmail.com). We will give preference to story proposals received by November 27, 2017.**

We plan to publish 12 stories (4 – 10 double-spaced pages or 800 – 2000 words) on this topic. Some additional stories may be published as online-only supplemental material. We also publish 2 – 4 commentary articles that discuss the stories that are published in the journal. To see a finished symposium you may access *Narrative Inquiry in Bioethics* Volume 3.1 for free on [Project MUSE](http://ProjectMUSE.org). For more information about the journal *Narrative Inquiry in Bioethics*, the guidelines for authors, and privacy policies, visit our webpage at: <http://www.nibjournal.org/authors/guidelines.html>

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