NIB Narrative Inquiry in Bioethics
A Journal of Qualitative Research

Call for Papers

Narrative Symposium: Patient and research participant experiences with genome-scale testing

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Narrative Inquiry in Bioethics will publish an issue devoted to personal stories about the experiences of individuals who have received results from genome-scale testing. This includes testing—in either a clinical or research setting—that produces a large amount of information about a person's genetic makeup (such as whole genome or whole exome sequencing, array-comparative genomic hybridization, or a comprehensive single nucleotide polymorphism profile). We are interested in the experiences of (i) adults who have undergone genome-scale testing for assistance with the diagnosis or management of a clinical condition, (ii) parents whose minor child has undergone such testing, and (iii) volunteers who have undergone genome-scale testing under a research protocol.

We would like to hear about both positive and negative experiences of receiving individual genomic information. The stories should give readers a sense of what it is like to undergo genome-scale testing, including the factors you considered when deciding whether to have such testing (or to have your child tested), your experience of the uncertainty about the kinds of information that might result, what it was like to get the results, and what could be done better in explaining this kind of testing and the results to people. We want your true, personal stories in a form that is interesting and easy to read. In writing your story, you might want to think about:

- Why did you decide to have genome-scale testing (or to have your child tested)? What did you hope to get out of such testing? What were your concerns?
- Did you understand what your doctor or the researchers told you about genome-scale testing before you made your decision? Is there anything you know now about this kind of testing that you wish you had known before you decided?
- Did you feel prepared for the possibility that something unexpected might be found?
- What was it like to actually get your (or your child's) results? What were the most positive aspects of getting the results? The most negative?
- How well did you feel that you understood your (or your child's) results? Is there anything that would have helped you to understand the information better?
- How has getting your (or your child's) genomic information affected your life in the short-term and long-term? Has the information led to any changes in the way you approach your health or life plans?
- Would you encourage friends or family members to participate in genome-scale testing? What advice would you give to them?

Every issue of Narrative Inquiry in Bioethics will be available electronically to over 1,000 institutional subscribers via ProjectMUSE.

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.

We plan to publish 10 to 12 brief 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 will also publish one or two commentary articles that discuss the stories that are published in the journal.

If you are interested in submitting a story, we ask you first to 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. We will give preference to story proposals received by March 26th.

For more information about the journal *Narrative Inquiry in Bioethics*, the guidelines for authors, and privacy policies, visit our webpage with Johns Hopkins University Press at:
http://www.press.jhu.edu/journals/narrative_inquiry_in_bioethics/guidelines.html

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PubMed and Medline will not index a new journal until it has published 4 issues across at least a 12 month period. Narrative Inquiry in Bioethics will be submitted for indexing in spring of 2011. We fully expect it will be indexed at that time and will include earlier articles published in NIB. (Note: All other medical ethics and humanities journals published by Johns Hopkins University Press are indexed in PubMed/Medline.)