

Recontacting patients in the age of panel testing: cancer genetic counselors' practice and perspective

Amy Mueller, Emily Dalton, Danielle Enserro, Catharine Wang, Maureen Flynn
Boston University School of Medicine, Boston, Massachusetts

Advances in genetic diagnostics and the interpretation of genetic information have inspired an ongoing discussion among genetics providers regarding the duty to recontact patients. This topic is acutely pertinent in cancer genetics given the recent availability of hereditary cancer panels that allow for rapid analysis of multiple genes associated with cancer development. This is a significant issue for cancer genetic counselors, who inform patients about cancer risks, provide counseling, and educate about testing options. The development of a position statement or practice recommendations on recontact in cancer genetics requires understanding the standard practice and perspective of cancer genetic counselors. From December 10, 2014- January 7, 2015 we conducted an online anonymous survey of cancer genetic counselors in the United States and Canada. Questionnaire domains included scope of recontact practice, factors influencing recontact practice, method of recontact, attitudes about recontact, and demographic and practice characteristics. A total of 52% of respondents reported that they have recontacted patients to offer updated diagnostic testing (66/127). Of those who reported recontact, 75% reported recontact to offer hereditary cancer panel testing and 80% to offer *BRCA1* and *BRCA2* deletion and duplication testing. Outside of direct recontact, education of other providers was the most reported method (57% of respondents) to access and educate patients on updated diagnostic testing. Respondents indicated that recontact is a shared responsibility between the provider and patient (43%), or, mostly patient responsibility (49%). There is not a consensus on how genetic counselors should approach the recontact of patients to offer updated diagnostic testing. This empirical data allows for an analysis of current practice and perspectives to inform several practice recommendations and the proposal of a position statement on recontact in cancer genetic counseling.