

The Innovative Use of RedCap as a Means to Re-contact Patients with Hereditary Cancer

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Introduction: Re-contacting patients with hereditary cancer improves compliance to cancer risk management, uptake of cascade testing, and healthy behavior interventions. However, as patient volumes increase, finding time to re-contact each patient can be a challenge. The use of a Genetic Patient Navigator (GPN) to re-contact patients with Hereditary Breast and Ovarian Cancer syndrome (HBOC) and Lynch syndrome (LS) has previously been described by our cancer genetics program. Here, we discuss the novel use of an online RedCap survey to assess the needs of HBOC and LS patients.

Methods: An internal department database was used to identify patients with HBOC and LS gene mutations previously seen in our Cancer Genetics clinics between 2011 and 2018. An online RedCap survey was designed to be distributed on an annual basis to our HBOC and LS patients with an email address. A reminder email was sent out at two and four weeks after the initial survey email. The majority of responses were collected over a two-month period. The survey included multiple choice and free response questions about cancer history and risk management, behavioral modifications, and cascade testing. The survey also included a variety of downloadable resources related to HBOC and LS.

Results: RedCap surveys were sent to 784 individuals with HBOC or LS, of whom 39 (5%) had an invalid email address and were excluded from further analysis. The response rate for this survey was 34.4% (256/745). Cascade testing was reported by 174 (67.9%) respondents. Behavior modifications, including changes to diet or exercise routine, weight loss, and smoking cessation, were reported by 190 individuals (81.5%). The most frequent request for GPN assistance involved referrals and scheduling appointments (55), followed by assistance with incorporating healthy behaviors (35), enrollment in a survivorship program (26), and coordinating cascade testing for at-risk family members (19). Assistance with smoking cessation was not requested.

Conclusion: Previously reported GPN data resulted in contact with 165 individuals out of 678 attempts (24.3%) over 24 months. The use of an electronic survey tool improved patient response rates by 41.6% and drastically reduced the time frame. This tool for re-contacting, data collection, and resource distribution allows genetics programs to efficiently identify and prioritize patient needs based on survey responses and track compliance over time. This method then permits genetics programs to reallocate time to contacting patients that either did not receive or complete the survey.