Always Better When We're Together: A novel, collaborative multi-stakeholder coalition enhances national guidelines for hereditary cancer testing and detection

Emily K. Dalton, Robert Pilarski, Lauren Sferrazza, Jessica Grzybowski, Ann Marie Miller, Shelly Cummings, Kelli Conlan, Kristen Postula, Rebecca Johnson, Lisa Schlager, Robin Dubin, Fred Struve

Although it is critical that national medical guidelines consistently incorporate the latest evidence regarding the potential benefits of hereditary cancer testing and/or accurately identify individuals who are eligible for such testing, gaps and discrepancies between and within guidelines exist. To address this, the Inter-Organization Cancer Genetics Clinical Evidence Coalition (INTERACT) was formed. The coalition is composed of genetic testing laboratories, industry organizations, and patient advocacy groups, all working together to advance medical guidelines for hereditary cancer genetic testing through collective engagement and evidence sharing with societal stakeholders. This work provides transparency and data on what the INTERACT coalition has accomplished since inception.

The INTERACT Coalition was established in 2020. Each member organization has agreed to a common charter and rules of engagement. The group has met monthly and routinely reviews National Comprehensive Cancer Network (NCCN) guidelines for areas of hereditary cancer testing inclusion. The NCCN produces the most used set of oncology practice guidelines and offers the greatest opportunity for collective impact. Other major medical society position statements have also been reviewed. The group assesses for inconsistencies between guidelines, as well as opportunities to refine or expand appropriate testing criteria based on review of relevant literature done by clinical representatives from each member group. These requests are compiled into a formal letter, reviewed for approval from each member organization, and submitted to the corresponding guideline panel through the submission request process.

Since 2020, 11 letters have been submitted to the NCCN across 5 expert panels (Genetic/Familial High-Risk Assessment: CRC; Genetic/Familial High-Risk Assessment: Breast, Ovarian, and Pancreatic; and the Kidney, Gastric, and Prostate Cancer treatment guidelines). A mean of 5 revisions are requested in each letter, with an approximately 20-40% (1-2 revision) incorporation rate for subsequent guideline drafts. To date, letters have not been submitted to other national guideline committees.

The INTERACT coalition demonstrates that a diverse group of stakeholders from industry and patient advocacy can work towards a common goal of increasing access to appropriate hereditary cancer testing. Through these collective efforts, INTERACT has successfully impacted the NCCN testing guidelines for hereditary cancer genetic testing, and demonstrated the utility of coordinated collaboration.