



## **The NSGC Genetic Counselor Research Repository Compendia**

Following the development of the NSGC Genetic Counselor Research Repository (formerly the NSGC Bibliography), the Payer Subcommittee has created compendia (collections of concise but detailed information about a particular subject) to highlight key articles that are important in various topics related to the value of genetic counselors. These topics include:

- Arguing the Business Case: Economic Value of Genetic Counselors
- Improving Patient Care: Clinical Value of Genetic Counselors
- Increasing Access to Genetic Services and Growing the Genetic Counseling Workforce
- Preventing Harm: Gaps in Patient and Non-Genetics Provider's Knowledge of Genetics
- Promoting Efficiency and Quality of Genetic Service Delivery

Key articles are identified through a search of the Genetic Counselor Research Repository using relevant key words and consultation with individuals who are content experts in each particular topic. Each article is reviewed by members of the Payer Subcommittee for relevance and importance for inclusion in the compendium.

### **Increasing Access to Genetic Services and Growing the Genetic Counseling Workforce**

This collection includes key articles that address key issues surrounding access to genetic services and discuss innovative solutions to expand the genetic counseling workforce and meet patient care needs.

Doyle N, Cirino A, Trivedi A, Flynn M. **Exploring Barriers to Payer Utilization of Genetic Counselors.** *J Genet Couns.* 2015 Feb;24(1):122-33. PMID: 25138080.

Surveys 263 medical directors and quality assurance directors at health insurance carriers throughout the United States in order to assess the barriers to expanded payer coverage of genetic counselors' services. "Evidence that use of genetic counselors improves health outcomes" led the list of factors having a significant/very significant influence on coverage policy. Findings demonstrate that some barriers to expanded reimbursement are more consistently identified as important and therefore more deserving of legislative and advocacy resources to effect change.

Kinney AY, Butler KM, Schwartz MD, Mandelblatt JS, Boucher KM, Pappas LM, Gammon A, Kohlmann W, Edwards SL, Stroup AM, Buys SS, Flores KG, Campo RA. **Expanding Access to BRCA1/2 Genetic Counseling with Telephone Delivery: A Cluster Randomized Trial.** *J Natl Cancer Inst.* 2014 Nov 5;106(12). PMID: 25376862.

Compares telephone and in-person counseling of women at risk for *BRCA1/2* mutations through a cluster-randomized clinical trial. They concluded that although telephone counseling leads to lower testing uptake, it appears to be as effective as in-person counseling with regard to minimizing adverse psychological reactions, promoting informed decision making, and delivering patient-centered communication for both rural and urban women.

Garcia C, Harrison K, Ring KL, Sullivan MW, Rauh LA, Medessitt SC. **Genetic counseling referral for ovarian cancer patients: a call to action.** Fam Cancer. 2019 Jul;18(3):303-309. PMID: 30993488.

Examines genetic counseling referral patterns in a cohort of 696 women diagnosed with ovarian cancer at one medical center. Referrals increased from 8% to 68% from 2004 to 2015; factors including staging and histology of cancer and family history were significantly associated with genetics referral, while older age and living >100 miles away were associated with decreased referral. Their data suggests that innovative strategies such as Medicare coverage for genetic counseling is needed to universalize testing.

Deutch N, Soo-Jin Lee S, Char D. **Translating genomic testing results for pediatric critical care: Opportunities for genetic counselors.** J Genet Couns. 2020 Feb;29(1):78-87. PMID: 31701594

Interviews with physicians, PAs, nurses who care for children with congenital heart disease (CHD) on their view on implementation of WES and WGS. Themes were (a) that clinicians felt they did not have sufficient training to accurately assess genetic results despite pressure to incorporate results into clinical decisions; (b), that they desire knowledge support from genetic specialists, such as genetic counselors, who both understand the critical care context and are available within the time constraints of critical care clinical pressures; and (c), that clinicians feel a pressing need for increased genetics education to be able to safely and appropriately incorporate GS results into clinical decisions.

Heald B, Plesec T, Liu X, Pai R, Patil D, Moline J, Sharp RR, Burke CA, Kalady MF, Church J, Eng C. **Implementation of universal microsatellite instability and immunohistochemistry screening for diagnosing lynch syndrome in a large academic medical center.** J Clin Oncol. 2013 Apr 1;31(10):1336-40. PMID: 23401454.

Characterizes three approaches for universal microsatellite instability and immunohistochemistry screening in a large academic medical center. When the genetic counselor was involved by contacting the patient to facilitate referral, time from referral to genetic counseling was significantly improved. They demonstrate that access to genetic counseling is an important factor in increased identification of patients with Lynch syndrome.

Cohen SA, Bradbury A, Henderson V, Hoskins K, Bednar E, Arun BK. **Genetic Counseling and Testing in a Community Setting: Quality, Access, and Efficiency.** Am Soc Clin Oncol Educ Book. 2019 Jan;39:e34-e44. PMID: 31099680.

Summarizes the need to improve access to genetic counseling and testing by discussing models for expanding access to underserved communities. Includes discussion of the importance of telehealth and collaboration of genetic counselors with non-genetics healthcare providers in community settings to maximize efficiency and access.

Maiese DR, Keehn A, Lyon M, Flannery D, Watson M; Working Groups of the National Coordinating Center for Seven Regional Genetics Service Collaboratives. **Current conditions in medical genetics practice.** Genet Med. 2019;21(8):1874-1877. PMID: 30686822.

Survey of 924 genetics professional to assess current practice and workforce need. Data demonstrates increased wait times and an increase in average new patient needs. When asked to rank what resources would help to serve their patients in the coming decade, technical assistance resources (e.g., insurance preauthorization and setting up telegenetics) were ranked highest). They also advocated for education for nongenetic health-care providers and the

development of standardized approaches to genetic services based on best practice and evidence-based guidelines.

Radford C, Prince A, Lewis K, Pal T. **Factors Which Impact the Delivery of Genetic Risk Assessment Services Focused on Inherited Cancer Genomics: Expanding the Role and Reach of Certified Genetics Professionals.** J Genet Couns. 2014 Aug;23(4):522-30. PMID: 24306140.

Discusses need to develop and refine genetic counseling strategies as the use of genomic testing technology increases, particularly given health care providers' limited knowledge and inadequate training. Advocates for policies that enhance access to genetics professionals, revise reimbursement schemes, and protect against potential discrimination based on genetic information.