



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.

Arguing the Business Case: Economic Value of Genetic Counselors

This collection includes key articles that demonstrate the economic value of genetic counselor involvement in service delivery, including cost savings and revenue generation. Note that articles that evaluated the economic value of genetic testing without reference to genetic counseling or genetic counselors were specifically excluded. The articles listed below include those that describe the billing and reimbursement patterns of clinical genetic services.

Test Utilization Management

Miller CE, Krautscheid P, Baldwin EE, Tvrdik T, Openshaw AS, Hart K, Lagrave D. **Genetic counselor review of genetic test orders in a reference laboratory reduces unnecessary testing.** Am J Med Genet A. 2014 May;164A(5):1094-101. PMID: 24665052.

GCs at ARUP Laboratories perform a pre-analytic assessment of complex molecular genetic test orders that includes reviewing clinical and family history information and considering the clinical utility and cost-effectiveness of ordered tests. A retrospective review of the GC-facilitated test changes over a 21-month period at ARUP laboratories found approximately 26% of all requests for complex genetic tests assessing germ line mutations were changed following GC review. The test review process resulted in an average reduction in charges to the referring institutions of \$48,000.00 per month. GC review of genetic test orders for appropriateness and clinical utility reduces healthcare costs to hospitals, insurers, and patients.

Riley JD, Procop GW, Kottke-Marchant K, Wyllie R, Lacbawan FL. **Improving Molecular Genetic Test Utilization through Order Restriction, Test Review, and Guidance.** J Mol Diagn. 2015 May;17(3):225-9. PMID: 25732008

This study examined the use of Genetic Counselors for utilization management in a laboratory setting to improve genetic test ordering and decrease genetic test spending. Implementing this, resulted in a decrease in genetic test ordering and a gross cost savings of \$1,531,913 since the

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inception of these programs in September 2011 through December 2013 at Cleveland Clinic. This article directly shows how the use of GCs in the laboratory UM setting has significantly decreased healthcare costs by ensuring appropriate test ordering for clinical indication.

Wakefield E, Keller H, Mianzo H, Nagaraj CB, Tawde S, Ulm E. **Reduction of Health Care Costs and Improved Appropriateness of Incoming Test Orders: the Impact of Genetic Counselor Review in an Academic Genetic Testing Laboratory.** J Genet Couns. 2018 Sep;27(5):1067-1073. PMID: 29427196.

The goal of this study was to evaluate the impact of genetic counselor (GC) review of incoming test orders received in an academic diagnostic molecular genetics laboratory (Cincinnati Children's Hospital). During this 6-month study, the GC team reviewed 2,367 incoming test orders. 4.6% of the orders were flagged for review for potentially inefficient or inappropriate test ordering. Modification was proposed for 96.08% of the flagged cases, which resulted in cost savings totaled \$98,750.64, for an average of \$2,015.32 saved per modification. The review of test orders by a genetic counselor both improves genetic test ordering strategies and decreases the amount of health care dollars spent on genetic testing.

Kotzer KE, Riley JD, Conta JH, Anderson CM, Schahl KA, Goodenberger ML. **Genetic testing utilization and the role of the laboratory genetic counselor.** Clin Chim Acta. 2014 Jan 1;427:193-5. PMID: 24084506.

This article discusses the roles laboratory genetic counselors play within hospital laboratories and genetic testing laboratories in increasing the appropriate utilization of genetic tests.

Billing and Reimbursement of Clinical Genetic Services

Gustafson SL, Pfeiffer G, Eng C. **A large health system's approach to utilization of the genetic counselor CPT® 96040 code.** Genet Med. 2011 Dec;13(12):1011-4. PMID: 21857230.

In this study, one institution tracked for the utilization of 96040 between January 2008 – February 2009 and analyzed reimbursement. Of 350 encounters tracked, 82% were billed to private payers. Of these, 62.6% received some level of reimbursement. No association was seen for denial when analyzed by the diagnosis code or by genetics focus. Through this model, genetics appointment availability minimally doubled. Using 96040 allowed for expanding access to genetics services, increased appointment availability, and was successful in obtaining reimbursement for more than half of encounters billed.

Bernhardt BA, Tumpson JE, Pyeritz RE. **The economics of clinical genetics services. IV. Financial impact of outpatient genetic services on an academic institution.** Am J Hum Genet. 1992 Jan;50(1):84-91. PMID: 1729898.

This study examined the total charges, payments, and collection rates for 5 different genetics clinic at one academic institution (John Hopkins). Although the rates varied between clinics, generally professional fee accounted for a low percentage of the. The study also found that for every \$3 paid to the academic institution for a genetics patient, \$1 reverts to the genetics division, while \$2 are paid to other departments. Conclusion and recommendations: 1. New means of supporting clinical genetic providers are needed. 2. Hospital administrators need to be educated about downstream revenues 3. Consider renegotiating the reimbursement rate (given that service provided are complex and multiple services done at one visit) 4. Revenues generated to the genetics lab should be used to support clinical genetic services. Although this study was published in 1992, conclusions from this paper may still be relevant today.

Bernhardt BA, Pyeritz RE. **The economics of clinical genetics services. III. Cognitive genetics services are not self-supporting.** Am J Hum Genet. 1989 Feb;44(2):288-93. PMID: 2912071.

This study examined the amount of time required to provide GC services, as well as the charges and reimbursement for genetic services in the prenatal, specialty, outreach, and pediatric genetics settings. In all clinic settings, less than ½ of total service time was that of a physician. In no clinic setting was genetic counseling self-supporting. The authors pointed out 3 main barriers: lack of a CPT code to charge of service, medical policies do not reimburse for GC services, and GCs not licensed. This paper provides a historical background on the economics of clinical genetic services even though specific charges and reimbursement may have changed.

Other

Schwartz MD, Valdimarsdottir HB, Peshkin BN, Mandelblatt J, Nusbaum R, Huang AT, Chang Y, Graves K, Isaacs C, Wood M, McKinnon W, Garber J, McCormick S, Kinney AY, Luta G, Kelleher S, Leventhal KG, Vegella P, Tong A, King L. **Randomized noninferiority trial of telephone versus in-person genetic counseling for hereditary breast and ovarian cancer.** J Clin Oncol. 2014 Mar 1;32(7):618-26. PMID: 24449235.

In a comparison of usual care (UC) or telephone care (TC), primary outcomes were compared for patients randomized into one group or another. Primary outcomes were: knowledge, satisfaction, decision conflict, distress, and quality of life; secondary outcomes were equivalence of BRCA1/2 test uptake and costs of delivering TC versus UC. There were no differences in primary outcomes for TC versus UC. Test uptake was lower in TC versus UC, and cost savings showed a savings of \$114/patient. Genetic counseling can be effectively and efficiently delivered via telephone to increase access and decrease costs.

Cragun D, Camperlengo L, Robinson E, Caldwell M, Kim J, Phelan C, Monteiro AN, Vadaparampil ST, Sellers TA, Pal T. **Differences in BRCA counseling and testing practices based on ordering provider type.** Genet Med. 2015 Jan;17(1):51-7. PMID: 24922460.

BRCA tested patients were surveyed to see if recommended pre-test counseling elements were included, and to determine if there was a higher likelihood of targeted (less costly testing) when a genetic counselor was involved. Both a higher recall of pre-test counseling was reported when a GC was included in the process. From a business standpoint, involvement of a GC reported to halve the chance of larger comprehensive testing.

Future Compendium Topics TBD:

- Improving Patient Care: Clinical Value of Genetic Counselors/Genetic Counseling
- 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
- Positions of Other Societies and Organizations: Evidence Based Recommendations Supporting Genetic Counseling