

Access and Service Delivery
Payer Subcommittee
Bibliography Search Tool
2018

Search Terms

Publication Type

1. **Editorial:** *Provides an opinion on behalf of the author.*
2. **Original Research:** *Primary literature.*
3. **Policy Statement:** *Organization-level document that prescribes acceptable methods or behaviors (e.g. NSGC, ACMG).*
4. **Practice Guidelines:** *Statements that include recommendations intended to optimize patient care, informed by a systematic review of evidence and an assessment of the benefits and harms of other care options.*
5. **Review:** *Overview of existing literature regarding a particular subject, which does not include original research of the authors.*
6. **Other:** *All other articles that cannot be classified above.*

Specialty

1. Adult (Including Complex Disease)
2. ART/Preimplantation Genetic Disorders
3. At-home/Direct-to-consumer testing
4. Cancer
5. Cardiac
6. Hematology
7. Metabolic
8. Molecular/Cytogenetics/Biochemical
9. Nephrology
10. Neurogenetic
11. Ophthalmology
12. Pediatric
13. Personalized Genomic Medicine
14. PGD/Preconception
15. Prenatal
16. Psychiatric
17. Public Health/Newborn screening
18. Other

Location of Study

1. United States
2. Canada
3. Other

Evaluated Healthcare Provider

1. Genetic Counselors
2. Other Genetics Healthcare Providers: *Geneticists (Clinical & Clinical Laboratory), Genetics Nurses*
3. Non-Genetics Healthcare Providers: *Physicians that are not boarded in Genetics (e.g. Surgeons, Primary Care Providers), Non- Genetics Clinical Care Providers (e.g. Physician Assistants, Nurses)*
4. Other Non-Specified Providers: *Genetics researchers not involved in patient care (e.g. social workers, other).*

Evaluated Outcome

1. Access/Referral to Genetic Services: *Articles regarding gaining entry into healthcare system, access to sites of care, access to genetics providers. Knowledge of providers to refer to genetics services.*
2. Accuracy of Risk Assessment: *Articles regarding the preciseness and process of healthcare providers evaluating the potential risks (specific to risk of being affected) of a hereditary condition. This would include the use of risk assessment models by healthcare providers.*
3. Decision-Making (Non-Patient): *Articles regarding the process of healthcare providers and healthcare organizations in the selection of a course of action among several alternative possibilities in regards to a patient's management*
4. Decision-Making (Patient): *Articles regarding the process of a patient (or supportive persons) in selection of a course of action among several possibilities regarding their own healthcare.*
5. Ethics/Legal/Social Implications: *Articles that include:*
 - a. *Privacy and fairness in using genetic information, including the potential for genetic discrimination in employment and insurance;*
 - b. *Integrating new genetic technologies into the practice of clinical medicine;*
 - c. *Ethical issues surrounding designing and conducting genetic research with people, including the informed consent process;*
 - d. *Educating healthcare professionals, policy makers, students, and the public about genetics and the complex issues resulting from genomic research.*
6. Health Technology: *(Definition of Health Technology) Application of organized knowledge and skills in the form of devices, medicines, vaccines, procedures and systems developed to solve a health problem and improve quality of lives. Articles that focus on implementing health technology in the genetics setting (e.g. use of electronic pedigrees). This category includes articles about using the software for a risk-assessment model.*
7. Implementation/Process Evaluation: *Articles that describe and/or evaluate whether program, clinic, or hospital activities have been implemented as intended and resulted in certain outcomes regarding genetics related healthcare.*

8. Informed Consent: Articles regarding the process of obtaining permission from a patient that allows a healthcare provider (e.g. genetics and non-genetics) to perform a test or procedure after the purpose was fully explained.
9. Models of Genetic Counseling: Articles regarding the evaluation of different modes of providing healthcare services, including:
 - a. The methods in which genetic counseling services are delivered;
 - b. The way patients assess them
 - c. The components unique to each service setting and how they affect the provision of genetics services [Cohen, et al, 2013].
10. Models of Genetic Counseling—Telegenetics: Articles that focus on evaluating the mode of providing genetics healthcare services at a distance (telegenetics—by phone and video).
11. Patient Coping and Psychosocial Outcomes: Articles that evaluate patient-specific efforts to reduce stress related to genetics healthcare (including provider involvement in these coping mechanisms). Articles regarding the evaluation of how psychological and social factors influence patient outcomes (e.g. patient anxiety).
12. Patient Harm: Articles regarding evaluation of patient harm (defined as: any unintended injury resulting from or contributed to by medical care (including the absence of indicated medical treatment), in the genetics setting. Patient harm can be evaluated with regard to genetics professionals and non-genetics professionals. This definition includes avoiding patient harm.
13. Patient Knowledge: Articles regarding patient awareness and knowledge with regard to genetics concepts (e.g. basic information, genetic testing, risks, and benefits) including prior to and after an intervention.
14. Patient Outcomes—Other: Any other evaluation of patient healthcare outcomes
15. Patient Satisfaction: Articles that evaluate the degree to which the patient is content with the healthcare he/she received from a healthcare provider with regard to genetics services (e.g. wait times, survey outcomes).
16. Preventative Care: Articles regarding documentation of instances that genetics healthcare help or do not help to prevent illnesses or diseases (e.g. prophylactic oophorectomy after identifying a hereditary cancer syndrome). Articles must reference the genetics healthcare that lead to preventative care.
17. Provider Knowledge: Articles regarding awareness and knowledge of the healthcare provider with regard to genetics concepts (e.g. basic information, genetic testing, risks, and benefits)
18. Revenue Generated/Cost Savings: Articles regarding the evaluation of genetics services in their ability to generate revenue or provide cost savings (to the patient, healthcare system, or other)
19. Utilization of Genetic Testing: Articles regarding the effective or ineffective use of genetic testing by a provider or organization.
20. Other: All other articles that could not be sorted as above