

American Academy of Nursing Releases Policy Brief on Strengthening Regulation of Laboratory-Developed and Direct-To-Consumer Genetic Tests

Academy Calls for Increased Consumer Privacy Protections and Education Regarding LDT and DTC Genetic Testing

Washington, D.C. (April 10, 2018) — The American Academy of Nursing released a policy brief that recommends actions be taken to increase the regulation of laboratory-developed (LDT) and direct-to-consumer (DTC) genetic testing. Concerns about consumer ease of access to genetic testing include test accuracy, consumer protections from discrimination based on results, and the lack of nursing's role in providing best practices, context and education.

Among the several recommendations in the Academy's policy brief is for the Food and Drug Administration and the Centers for Medicaid and Medicare Services to work with entities that own and market commercial test "kits" or laboratory-developed genetic tests and services regarding the clarity of information provided to consumers.

Genetic testing includes an array of techniques for analyzing human DNA, RNA, and protein. These services range from detecting gene variants associated with a specific disease to paternity testing. The increased ease of access to genetic testing for the general public over the past decade has given rise to issues regarding data storage, testing standards, false-positives, and consumers understanding the true meaning of a test within the context of risk factors. Privacy of the results is also a concern as data could potentially be used in discriminatory practices by insurers and employers.

The Academy's policy brief, "Strengthen Federal Regulation of Laboratory-developed and Direct-To-Consumer Genetic Testing," was published in the Academy's journal, *Nursing Outlook*.

"The American Academy of Nursing has long advocated for all patients' rights to information, education and privacy related to their health care," said Academy President Karen Cox, PhD, RN, FAAN. "The Academy is interested in working with external stakeholders including consumer organizations to increase nurses' role in genetic education for patients and families and in disseminating best practices for genetic testing for healthcare providers and consumers."

Read the Academy's full policy brief: http://www.nursingoutlook.org/article/S0029-6554(17)30629-2/fulltext

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CONTACT:

Barry Eisenberg 202-777-1174 Barry Eisenberg@aannet.org