Center for Translational & Policy Research on Precision Medicine

Economic, Financial, and Policy Implications of Genetic Testing for Alzheimer's Disease and Related Dementias

Overview:

Alzheimer's Disease and Related Dementias (ADRD) have long challenged clinicians, researchers, and policymakers as the only leading causes of death in the United States without disease-modifying treatment. One of the most common risk factors is the ε4 allele of the apolipoprotein E gene, APOEε4, which has been the focus of intense research and lay public interest. While APOEε4 is associated with an increased risk for late-onset AD, on its own it has not been found to have clinical validity and utility. Clinical guidelines recommend against APOE testing, either direct-to-consumer (DTC) or clinician ordered. The dynamic surrounding APOE testing, including consumer access to testing despite the lack of known clinical utility and with results provided to consumers outside of the clinical care context – represents an overarching challenge that we believe will increasingly become a clinical, economic, and policy conundrum.

Objectives:

We are developing conceptual frameworks and methodological approaches to examine the economic, financial/coverage, and policy implications of genetic testing for ADRD risk and conducting initial analyses in the following areas:

1. **Coverage policies for ADRD genetic testing**
2. **Role of physicians in managing patients who present their APOE DTC testing results**
3. **Economic value of ADRD genetic testing**

Our focus is APOE testing for late-onset AD because of its availability via DTC testing. However, we are placing this work into the larger context of testing for other ADRD risk factors and thus considering a range of genetic risk variants, dementia types (e.g., frontotemporal dementia, Lewy Body Dementia), and forms of disease (early- vs. late-onset; familial vs. sporadic).

TRANSPERS

Launched in 2008, the Center for Translational and Policy Research on Precision Medicine (TRANSPERS) at the University of California, San Francisco is a first-of-its-kind research center dedicated to developing evidence-based information for patients, providers, industry, researchers and policymakers to objectively assess how personalized medicine can be most beneficial and efficient in improving health outcomes. The TRANSPERS Center has been funded by grants from the National Institutes of Health (NIH) and several foundations.

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