Ensuring Equitable Access to Genetics-Informed Alzheimer's Prevention and Treatment

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1. Executive Summary

Alzheimer's disease is a neurodegenerative disease that progresses over time and is influenced by genetics as well as by biological processes. According to research, genetic risks (most importantly APOE-ε4 allele) have a huge impact on determining who will develop Alzheimer's disease and at what rate (Alzheimer's Association). New advances in biomarker research and new drugs have caused us to shift to earlier biological diagnosis and treatment of Alzheimer's disease (Jack et al., 2013; Cummings et al., 2024).

Unfortunately, not all communities have access to the same level of genetic testing, biomarker testing, or newer treatments for Alzheimer's. Many underserved populations still do not have early diagnoses or access to the latest advancements in dementia care. If we do not make an effort to change policies in order to address the inequities in access to genetic risk assessment and biomarker diagnostic testing, we will exacerbate the existing disparities between populations rather than eliminate them. This policy brief advocates for a federal policy that includes genetic risk assessments and biomarker diagnostic tests as part of standard of care for Alzheimer's disease and ensures equitable access for all underserved communities.

2. Background / Context

- Understanding Underserved Communities

Underserved communities are those populations that have barriers to accessing health care, such as income and geographic location, and have been disadvantaged based on race and ethnicity. These barriers to health care often lead to people being diagnosed with Alzheimer's disease later than they should have and having less opportunity to have genetic tests.

- Scientific Background

Alzheimer's disease has a history of over 100 years. The abnormal plaques and neurofibrillary tangles that became the focus of the earliest research on Alzheimer's were first described by Alois Alzheimer in 1906, when he examined the brain of a patient suffering from memory loss (Köhler et al.). Today, these same pathological findings continue to be at the heart of Alzheimer's research. While our knowledge of the disease has grown over the past century, Alzheimer's is recognized as a biological disorder that results from the interaction of multiple biological and environmental risk factors rather than as a typical part of the aging process.

One of the main factors involved in Alzheimer's is genetic predisposition. The Alzheimer's Association identifies that there is a significant genetic component in Alzheimer's risk, particularly in the presence of the APOE-ε4 allele. Different ethnic and racial groups tend to have different experiences with Alzheimer's. As a result, culturally competent care may also be of paramount importance in the assessment and treatment of these groups.

- Current Research Climate

Alzheimer's research is rapidly evolving. The 2024 drug development pipeline demonstrates that research is progressing toward developing drugs that are aimed at modifying the disease at its earliest stages (Cummings et al., 2024). Consequently, access to biomarker testing and genetic risk assessment is increasingly important in determining who is eligible to participate in these treatments.

3. Problem Statement

There have been significant advancements in the biotechnology of Alzheimer's genetics, biomarker research, and medication development; however, current public health policies do not reflect this development adequately. The advancement of genetics-based Alzheimer's care will undoubtedly elevate today's already poor health inequities by exacerbating barriers to access and coverage.

Impacts

- Delayed diagnosis for people with limited access to biomarker testing
- Unequal availability of genetic counseling and risk assessment services
- Decreased access to novel treatments that require early identification
- Increased health disparities for underrepresented populations

Why Current Policy Is Insufficient

- Emphasize late-stage care rather than prevention and early detection
- Lack standardized coverage for genetic and biomarker testing
- Do not address disparities in access to specialized Alzheimer’s services

4. Policy Proposal and Analysis

- Policy Proposal

The proposed and reasonably supported establishment of the GAEP (Genetics-Informed Alzheimer's Equity) Program at the Federal level would enhance the availability of genetic counseling, biomarker diagnostics, and early intervention for people across all demographics.

- Scientific Justification

Jack et al. (2013) established a timeline depicting that with the use of biomarkers, abnormalities associated with Alzheimer's disease could be diagnosed 10-20 years before a patient becomes cognitively symptomatic. These biomarker assessments can be performed through imaging or by testing cerebrospinal fluid and/or blood, and they allow intervention to begin as early as is biologically possible.

In addition, the hypotheses arising from supportive genetic and molecular evidence show that amyloid deposits in the brain correlate to both cognitive decline and progression of Alzheimer's disease. continue to influence the future of Alzheimer's Drug Development (Hardy & Selkoe, 2002); however, the increasing drug pipeline also highlights the need for early biological models of care (Cummings et al., 2024).

Analysis

- Benefits

Accurate identification of patients allows earlier diagnosis and more effective treatment, leading to improved outcomes and evidence-based targeted treatment for patients and therefore the need for a more efficient allocation of healthcare resources through the slowing down of disease progression. Additionally, reducing the disparities in access to advanced Alzheimer's care.

- Challenges
    - Ethical issues surrounding genetic (biological) information privacy;
    - Lack of proper diagnostic infrastructure in many rural and underserved areas;
    - Need for more healthcare provider training in the area of genetics-informed or biological-classified care.

5. Specific Policy Recommendations

- Standardize Coverage for Genetic and Biomarker Testing

Mandate the public healthcare programmes to provide coverage under their existing funding streams for genetic (APOE) and biomarker testing for those at risk of developing Alzheimer's Disease.

- Expand Genetics-Informed Alzheimer's Screening Programs

Fund community-based screening initiatives that integrate genetic risk assessment and biomarker testing, particularly in underserved regions.

- Increase Provider Training in Alzheimer's Genetics

Invest in community-based programs that facilitate integration of both genetic risk assessment and biomarker testing, with a focus on underserved communities and individuals.

- Ensure Equitable Access to Emerging Treatments

Support the professional development of healthcare providers by providing training on ethical genetic counselling, biomarker interpreting and early intervention.

- Integrate Research into Public Health Policy

Create a standard protocol to ensure that access to any newly approved therapies or medications will not be determined by a patient's income or where they reside (geographically).

6. Conclusion

Research into Alzheimer's has moved successfully to a model of patient care that is more driven by genetics and the biologic markers of the disease. By utilizing this knowledge and advancing our understanding of neurodegenerative diseases, we are able to diagnose patients earlier in their progression and develop treatments that will be highly effective. At the same time, without appropriate policies to ensure that all population groups have equal access to these approaches, we create disparities in access to Alzheimer's care. A policy that is informed by genetics and focused on equity will help ensure that the scientific advancements we are achieving will ultimately translate into significant improvements in public health. Aligning policy for the provision of healthcare with the scientific research already established regarding Alzheimer's will also assist in the promotion of innovation as well as fairness in the treatment of neurodegenerative diseases.

Works Cited

"Alzheimer's Association - Wiley Online Library." *Alzheimer's Association*, alz-journals.onlinelibrary.wiley.com/.

Alzheimer's Association. "Is Alzheimer's Genetic?" *Alzheimer's Disease and Dementia*, Alzheimer's Association, www.alz.org/alzheimers-dementia/what-is-alzheimers/causes-and-risk-factors/genetics .

Hardy, John, and Dennis J Selkoe. "The Amyloid Hypothesis of Alzheimer's Disease: Progress and Problems on the Road to Therapeutics." *Science (New York, N.Y.)*, vol. 297, no. 5580, 2002, pp. 353–6, https://doi.org/10.1126/science.1072994.

Jack, Clifford R, et al. "Tracking Pathophysiological Processes in Alzheimer's Disease: An Updated Hypothetical Model of Dynamic Biomarkers." *The Lancet Neurology*, vol. 12, no. 2, Feb. 2013, pp. 207–216.

Neundörfer, Gabriele, and Hanns Hippius. "The Discovery of Alzheimer's Disease." *Dialogues in Clinical Neuroscience*, vol. 5, no. 1, Mar. 2003, p. 101, www.ncbi.nlm.nih.gov/pmc/articles/PMC3181715/.