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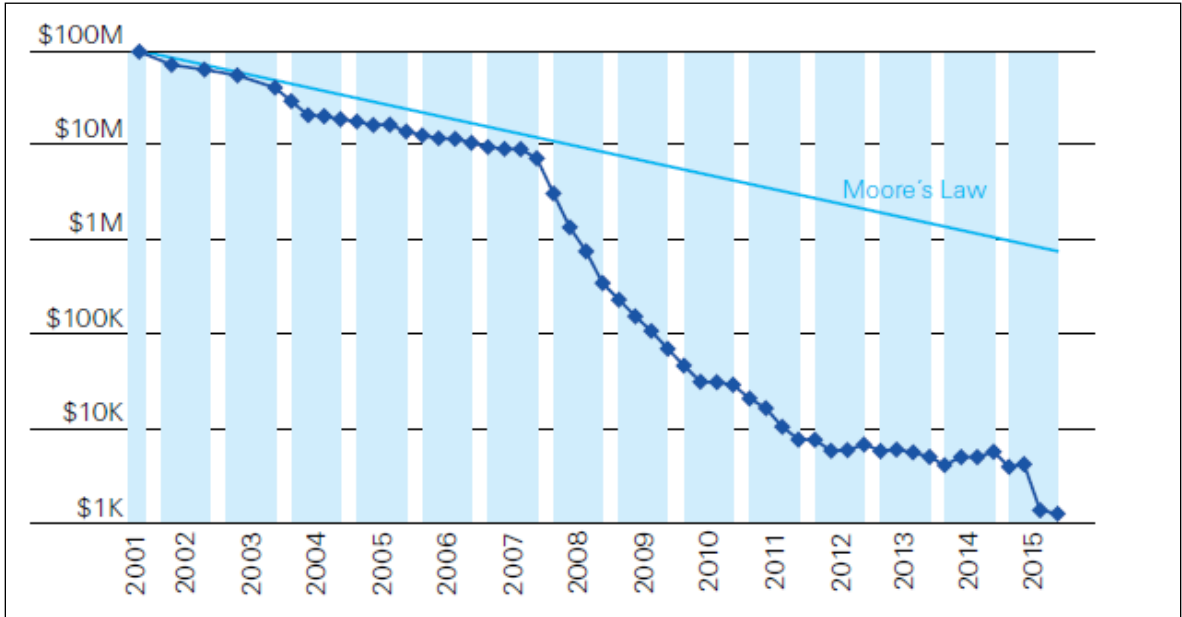
Abstract for Research Paper

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|--------------------------------------|---|
| Title | Impact of Genetic Testing on Insurance and Retirement Planning |
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Background

Genetic research has increased tremendously, and predictive genetic testing & genomics market will reach \$4.6 billion by 2025. With medical advancements and cheaper genetic tests, several genetic variants are uncovered including the greater risk conferred for Cancer, Parkinson's, Alzheimer's etc.

Figure-1: Cost per genome



National Human Genome Research Institute: <https://www.genome.gov/sequencingcostsdata/>

Table 1: Genetic testing methodologies

| Technology | Rare diseases | Common diseases | No. of genes tested | Turn-around time | Approx. cost |
|------------------------|---------------|-----------------|---------------------|------------------|------------------|
| SNP microarrays | Moderate | Poor | Thousands | Days to weeks | \$100s |
| Single-gene sequencing | Good | Poor | One | Weeks | \$100s – \$1000s |
| Panel sequencing | Moderate | Good | Few – Hundreds | Weeks to months | \$100s – \$1000s |
| Full genome sequencing | Good | Good | All | Weeks to months | \$1000s |

National Human Genome Research Institute: <https://www.genome.gov/sequencingcostsdata/>

Genetic tests can be:

1. Prenatal to detect changes before birth
2. New-born screening
3. Diagnostic testing to identify specific genetic conditions in symptomatic individuals.
4. Carrier screening to identify autosomal recessive diseases.
5. Predictive / Pre-symptomatic testing for estimating future risk
6. Pharmacogenetic testing to guide individual medicine usage
7. Preimplantation testing to reduce risk of having children with genetic / chromosomal disorders.
8. Nutrigenetic testing to study genetic variations on interaction between diet, health etc.

These tests quite accurately predict risks to encourage preventative steps. A famous example is Angelina Jolie undergoing mastectomy after discovering her gene mutation BRCA1 that raises risk of breast cancer. After this, referral increased 250% [from 1981 (2012) to 4847 (2013)] and grows at 200% since 2013 with more enquiries for risk reducing mastectomy.

On the positive side: the biggest concern people have when saving is whether they will outlive their money. These tests can help people refine those estimates.

Table 2: Genetic Test Criteria

| SI | Validity | Details |
|----|------------|---|
| 1 | Analytical | Detect and measure presence of genetic variants accurately |
| 2 | Clinical | Divide a population into groups based on risk or outcomes |
| 3 | | Demonstrate improvement in actionable outcomes (prevention, prognosis, diagnosis, treatment, or management) of impairments. |

Source: Merker JD, et al. J Clinical Oncology

Table 3: Genetic Variations

| SI | Type | Probability |
|----|---------------------------------|-------------|
| 1 | Pathogenic | >99% |
| 2 | Likely pathogenic | 90 – 99% |
| 3 | Variant of unknown significance | <90% |

Source: Biesecker LG, et al. Distinguishing Variant Pathogenicity from Genetic Diagnosis. JAMA 2018

There are issues too: Insurers broadly welcome genetic testing for effective treatment and preventive action, but there is potential anti-selection due to information asymmetry. The impact on pricing could be adverse and impact mortality and morbidity and influence lapsation. In India, without centralised medical data, this could be severe. Anti-selection is exacerbated through differing regulations.

1. China: government has strict rules and ownership of citizen DNA data.
2. Singapore: no specific legislation forbidding insurers using DNA testing
3. Australia: consumers must disclose any DNA test results to insurers.
4. UK: genetic tests results unusable for insurance except for Huntington’s disease.
5. Europe: Most countries banned insurers from accessing private genetic tests.
6. USA: Genetic Information Non-discrimination Act, 2008) prevents insurers from denying coverage based on genetic predispositions.
7. Canada: Genetic discrimination law prevents insurers using results of genetic tests

8. India: while there is no specific anti-discrimination law now Delhi High Court ruled against discrimination in health insurance by United India Insurance involving a person with a heart condition which was perceived to be a genetic disorder by holding “Discrimination in health insurance against individuals based on their genetic disposition or genetic heritage, in the absence of appropriate genetic testing and laying down of intelligible differentia, is unconstitutional”. Insurance Regulatory and Developing Authority has directed insurers to remove “Genetic Disorders” from exclusions in new health insurance policies.

Insurers should safeguard interests without violating law and improve underwriting and design products. So, we need to analyse potential impact on industry and impact on customers. This trend will only increase, and effective steps are required to ensure:

1. Customers’ and Insurers’ interests are protected
2. Adequate planning
3. Safeguards are built into underwriting philosophy and regulations

Genetic risk prediction is powerful and a potential threat if not studied beforehand. The present paper aims to study:

1. Extent and maturity of genetic testing for comparison and best practices purposes if needed.
2. Application for insurance
3. Identify effective measures taken, best practices followed and the learnings that can be replicated

Context

With these challenges facing Insurers, we should ensure planning or the human cost would be huge. This paper attempts to study these areas and identify remedial measures. Learnings from this paper can help in identifying impacts and enable best practices.

Approach

Due reference will be made to medical and industrial journals, websites of Research Institutions, Insurers, Regulators etc. Inductive Research Approach is planned.

Observations/Results

Issues with genetic testing are real and conservative estimates show following effects of restricting use of genetic test results in underwriting:

1. Life Insurance: increase of 1-3% premiums and average mortality rates by 35% (males) and 60% (females) with only six genetic disorders included in analysis.
2. CI: 26% increase in the average CI claims rate (+16% for males and +41% for females)

Ban on using genetic test results in insurance could affect the industry's ability to adjudicate claims, as genetic tests are now becoming integral to clinical diagnostics. Further genetic testing can improve patient care and could be incorporated into insurance products for customers benefit.

Structure

The proposed ToC of the paper is:

1. *Executive Summary*
2. *Table of Contents, including lists of figures and tables*
3. *Methodology of research and the Material used*
4. *Understanding insights from genetic tests applied in major economies*
5. *Identify:*
 - a. *Impact, scope and potential of genetic tests for financial planning*
 - b. *Synergies between the genetics/health and Insurers*
6. *Comparative study of regulations and legal position across geographies*
7. *Identify best practices and learnings*
8. *Opportunities for society, institutions & individuals*
 - a. *Government & Social Bodies*
 - b. *To Insurers, retirement systems & other industries*
9. *Interventions to improve & reinforce positive changes:*
 - a. *Medical/Technological – Tools, Information Technology Initiatives etc.*
 - b. *Regulatory*

c. *others*

10. *Conclusion*

11. *Suggestions for utilizing the learnings in the two industries*

12. *Appendix, Citations & Bibliography*

References

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2. If Underwriters of Individual Critical Illness Insurance Had No Access to Known Results of Genetic Tests. Canadian Institute of Actuaries Report to CIA Research Committee. 2016 Jan: <https://www.cia-ica.ca/docs/defaultsource/2016/216002e.pdf>
3. Website of National Human Genome Research Institute