Mythology, Science & Insurance

David Paul
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The Fates

Clotho ~ Lachesis ~ Atropos
The Three Fates

Clotho
   – spinner of the thread of life

Lachesis
   – measured the length of the thread

Atropos
   – cut the thread

*No-one, not even the Gods, could change the decisions of the Fates*
Content

Mythology
Science revision!
Disease and Insurance
Insurers’ fears
Three models around the globe
U.K. experience since 1997
The road ahead
... the basics of the science ...
“The Secret of Life”
50th Anniversary

• *Nature* journal, 2 April 1953
  – “A Structure for Deoxyribose Nucleic Acid” (DNA)
• James Watson (35) – zoologist
• Francis Crick (47) – physicist
• Maurice Wilkins, Rosalind Franklin

*Nobel Prize 1962*
This figure is purely diagrammatic. The two ribbons symbolize the two phosphate-sugar chains, and the horizontal rods the pairs of bases holding the chains together. The vertical line marks the fibre axis.
Nuestro viaje ...
DNA molecule

Single strand

- guanine
- cytosine
- adenine
- thymine

Two strands joined by base pairs
Base pair

phosphate

sugar → base

replication
Human Inheritance

Representation of the 23 paired chromosomes of the human male
Single-gene Conditions

Single gene mutation known to bear a close relationship to a particular illness

Dominant – ill if you inherit one copy of mutation from one parent

Recessive – ill if you inherit two copies of mutation
Recessive Single-gene Conditions

carrier father

Nn

carrier mother

Nn

NN

Nn

Nn

nn

normal

carrier

carrier

affected
Example of Recessive Single Gene Condition

- Cystic fibrosis
- 1 in 25 of UK population are carriers
- If both parents are carriers then 1 in 4 chance of offspring having both copies defective
- Defective gene “tracked down” in 1990
- Symptoms manifest in childhood
- Predictive testing has never been an issue for insurers
Dominant Single-gene Conditions

- Affected Father: Dd
- Normal Mother: dd

- Dd x dd → 1/2 Dd (affected) 1/2 dd (normal)
  - Affected: Dd, affected
  - Normal: dd, normal
  - Affected: Dd, affected
  - Normal: dd, normal
Example of Dominant Single Gene Condition

- Huntington’s Disease
- 1 in 18,000 of UK population are “carriers”
- If one parent is a carrier then 50:50 chance of offspring having one defective copy
- Defective gene “tracked down” in 1993 – to a position on chromosome 4
- Symptoms rarely manifest before age 35
- Predictive testing raises the prospect of applicant having knowledge that is denied to an insurer
Multi-gene disorders

The prospect that in the longer term it will be possible to draw links between patterns involving many genes, possibly allied to other physical and environmental factors, and occurrence of disease
CGGCACGATGCATGCTGCGTCCTGATCGACTCATCAGCTGACGTCAGCGCGACTGCATCCGATGTCGATCGAGCACTGAGTGACTGCTACATCATGCATGCTAGATCGATCGCATGATCGAC...CATCGCATCGATCTAGCATCGATGTACGTCTAGTAAATGCTGCTACGCTTATGCAGCTAGCGCGCAGCATGTACGACCGATGCATGATGCCTAGCTACATGCATGCTGACATGCTGACGCG
Impact on Insurers
Mid 1990’s

Predictive testing becomes possible and practical:
- cystic fibrosis (recessive) - DNA analysis can reveal whether a person is carrying a single defective copy of the gene
- Huntington’s (dominant) - DNA analysis can reveal, before age of onset, whether the disease has been passed on from an infected parent

Insurers:
- feared the prospect of applicants for insurance who know the secrets of Clotho, Lachesis and Atropos!
Some grounds for insurers to fear if ...

• Inherited diseases with onset in later life, no pre-onset symptoms
• Occurrence in significant numbers
• High proportion of potential sufferers submit themselves to screening by DNA analysis
• Screened sufferers take out lots of insurance!
But some of the fear is baseless

- There are many diseases with genetic causes but most manifest themselves with symptoms and insurers know as much as is known by the applicant for insurance ~ cystic fibrosis
- Much less frequently encountered are diseases where a DNA test can reveal a significant risk of disease in later life, for a person who is healthy and without symptoms ~ breast & ovarian cancer
- Widespread screening programmes are not a reality - not in immediate prospect
But some of the fear is baseless (continued)

- It should not be assumed that persons at risk will undergo testing - especially where there is no treatment, the “knowledge” is arguably not “useful” ~ Huntington’s
- For someone with a genetic condition - insurance is still a “gamble” on very long odds
Arguments against DNA tests disclosure to insurers

- Information is too private and regarded as intensely personal
- Unacceptable to Society - compare with racial discrimination
- Fear of having large numbers of uninsurable people .... “genetics under-class”
- .... “through no fault of their own” - “beyond the individual’s control”
- discourages people from undergoing DNA tests from which they would clinically benefit
Three Models  (1) “classic”

Light constraints

• with fewer constraints, an insurance market subscribes to the principle of symmetry of information between applicant and insurer

• insurers will not require applicants to submit to tests - but will want results of known tests, already undergone, to be submitted to them

Examples

Life insurance in US and Canada - although ...
# US Life Insurance State laws

<table>
<thead>
<tr>
<th>Requirement</th>
<th>States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed consent (12)</td>
<td>Arizona, Arkansas, California, Delaware, Kansas, Maine, New Jersey, New Mexico, Oklahoma, South Carolina, South Dakota, Vermont</td>
</tr>
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Three Models (2) “regulated”

Legislated prohibition of disclosure of DNA tests to insurers

• existing legislation, pre-dating the mid-1990’s and before practical DNA testing, may already constrain insurers from accessing medical or family history information

• privacy and confidentiality given weight to through statute

• principle of community rating may prevail in some markets
Three Models (2) “regulated”

Examples

Most European countries

- 1997 Convention on Human Rights and Biomedicine (Council of Europe) Article 12
  - limits … testing …. to health purposes or scientific research
- Ratified by Denmark, Greece, Portugal, Spain, Cyprus, Czech R., Estonia, Hungary, Lithuania, Slovakia, Slovenia
- Not signed nor ratified - Austria, Belgium, Germany, Ireland, Malta, UK

Medical insurance often features restrictions on rating for age or state of health
Three Models  (3) “hybrid”

Voluntary “moratorium” - codes of practice - not legislation
Disclosure of DNA tests contemplated in tightly controlled circumstances
Three Models  (3) “hybrid”

- development of science / medicine regarded as too fast-moving for legislation to cope
- disclosure of DNA tests may be prohibited for policies deemed to be of “normal” size and regarded as “social good”
- statistical and clinical relevance of a DNA test have to be demonstrated
- insurers undertake to use genetic data in a sensitive and confidential way - reliance on well-trained underwriting staff
Three Models (3) “hybrid”

Examples - UK, Ireland, Australia

In fact most countries feature both regulated and classic features in different insurance sectors
United Kingdom
a case study of the “hybrid” model
1997
UK Human Genetics Advisory Committee

The Implications of Genetic Testing for Insurance, 1997

- Permanent ban on insurers “inappropriate”
- Moratorium
- Disclosure of particular genetic tests only acceptable when a quantifiable association had been established ….. “actuarially relevant” for a specific insurance product
1998
Association of British Insurers (ABI)
Code of Practice

- Moratorium – mortgage-related life assurance for up to £100,000
- ABI list of predictive tests it proposed to use (above £100,000 and non-mortgage related business)
- Genetics and Insurance Committee (GAIC) established to demonstrate “actuarial relevance”
ABI list from 1998

Submitted
- Huntington’s
- BRCA1
- BRCA2
- APP
- Presenilin-1 (PS1)

Not submitted
- Familial adenomatous polyposis
- Hereditary motor and sensory neuropathy
- Myotonic dystrophy
- Multiple endocrine neoplasia
- PS2
<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
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<tbody>
<tr>
<td>October 2000</td>
<td>GAIC approved Huntington’s test for life insurance products</td>
</tr>
<tr>
<td>December 2000</td>
<td>ABI submission deadline</td>
</tr>
<tr>
<td>April 2001</td>
<td>hearings of Commons Select Committee on Science &amp; Technology</td>
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<tr>
<td>May 2001</td>
<td>UK General Election</td>
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<tr>
<td>October 2001</td>
<td>5 year moratorium forced on ABI by government £500,000 ~ all products</td>
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<tr>
<td>Mid 2002</td>
<td>GAIC re-constituted and a new chair and mostly new membership</td>
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2001 - 2006
Current State of Play

• GAIC about to issue new guidance on how ABI make applications for tests to be approved for use by the insurance industry
• We are midway through 2001-2006 moratorium
• Government advisors (Human Genetics Commission, HGC) stated wish to “further examine” the use of family history information? <a proxy for genetic information>

List of tests from ABI does not seem to be getting longer
Pointers for the road ahead
Genetics

- Scientific advances are remarkable and there is the prospect of major advances in the understanding and treatment of major disease
- Insurers need to understand it! Don’t be frightened of it!
- The predictive capability has sometimes been overstated
- The major disease groups - cardio-vascular and cancers - will not have their secrets traced to a simple genetic explanation
Recognise you need a balance

Don’t impede healthcare or research
Privacy & confidentiality (human rights)
Society’s desire for “inclusive” approach
Deep-seated public fear of insurers or employers being privy to intensely personal data

Use an approach which copes with current reality
Discuss an approach that will cope if DNA tests become prevalent and are heavily predictive
Never underestimate the competition!