An Ethical and Legal Perspective on Personalized Medicine and Genetic Discrimination

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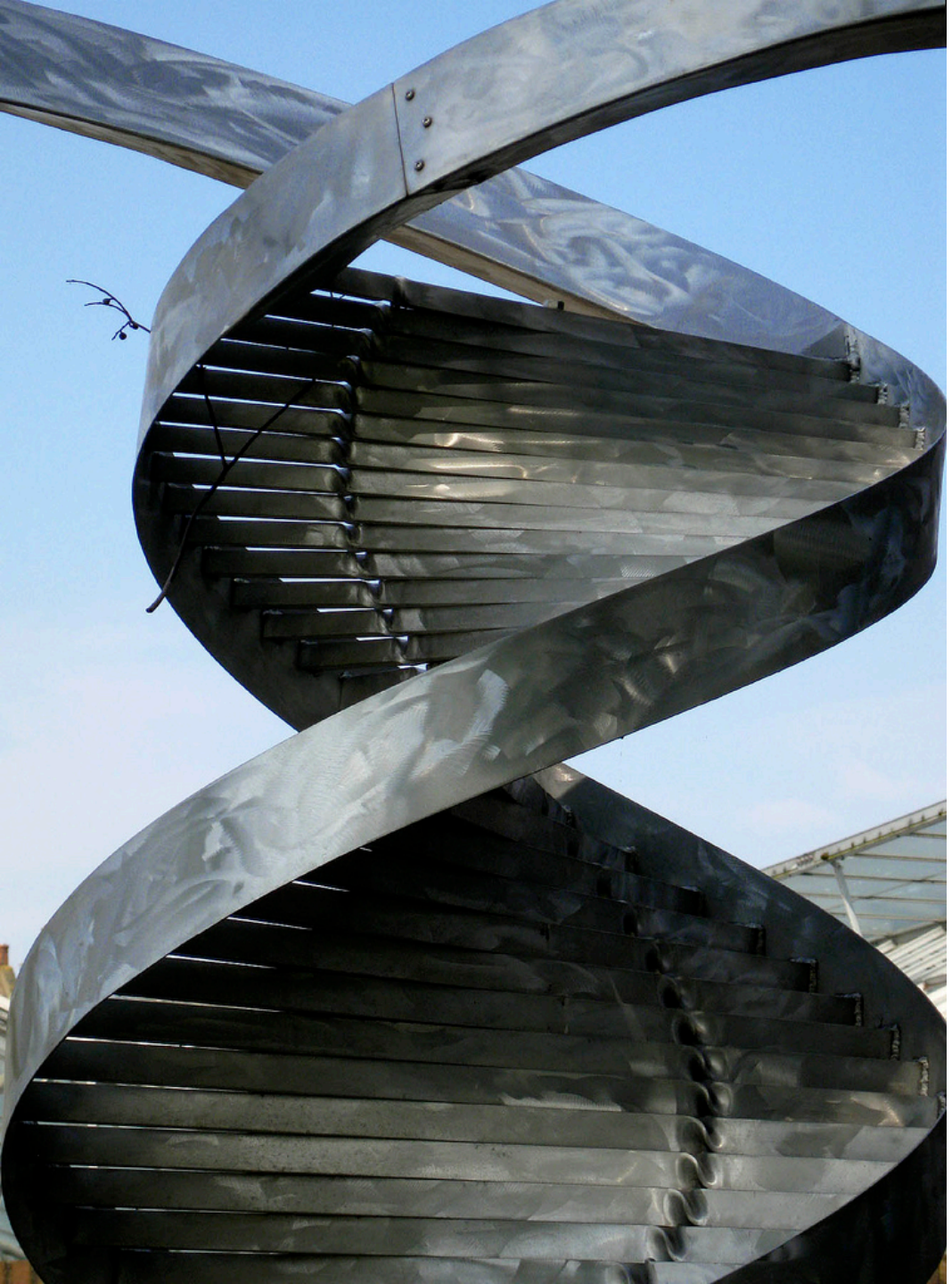


Should insurers be allowed to use genetic information?

Yes, insurers should be able to access genetic test results

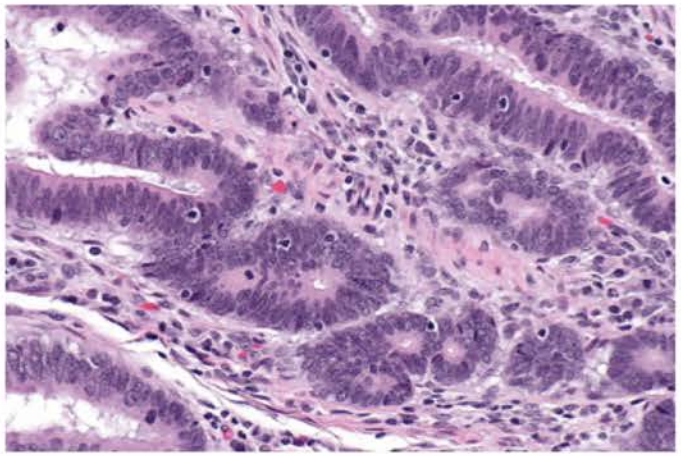
- Assess actuarially fair premium levels
- Avoid adverse selection
- Avoid death spiral

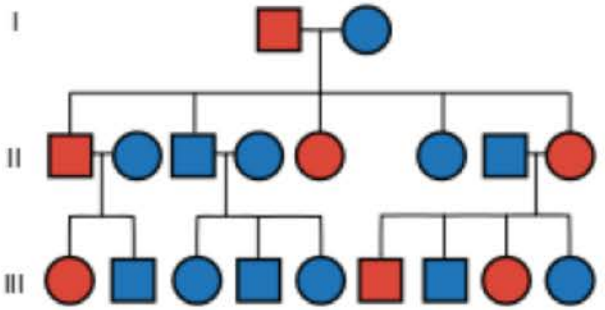
No, insurers should not be able to access genetic test results

- Access to insurance
- Privacy
- Assuage fear of genetic discrimination

Fear of genetic discrimination

Miki Yoshihito




I
II
III


Ins rance
Po icy

Case studies

Goal: To understand effectiveness and consequences of different policy mechanisms to address insurer use of genetic information

- Insurers have voluntarily agreement barring use of most predictive genetic test results
- Monetary cap
- Review system

- Non-discrimination legislation passed in Parliament in 2017 that bans the use
  - Undergoing constitutional challenge

- Insurers can use genetic test results
- Only if they have statistical evidence
- 2018 Parliamentary Report calls for moratorium

- Federal law (GINA) prohibits health insurers from using genetic information
  - Does not extend to other insurance

Semi-structured interviews

- Interviewed stakeholders from government, insurance, medical genetics community, advocacy community, and academia
- Canada – May 2016 – 19 stakeholders
- UK – June 2016 – 22 stakeholders
- Australia – March 2017 – 17 stakeholders
- Interviews recorded and transcribed
- Qualitative analysis using MAXQDA

Findings

- Fear of genetic discrimination heightened in Canada and Australia
- UK Moratorium relatively effective for both insurers and patients
- Areas of contention
  - How useful is genetic information to insurers?
  - Can insurers be trusted to get science right?

UK Advocacy

"…The insurance industry realized that actually not all genetics was like Huntington's disease. You know that Huntington's disease is way out on the end of a continuum of predictability, and if you look around you… most people still live to be about eighty, and most people die of dementia, skeletal failure, heart failure, or cancer, and these are not – although they have a genetic element they're not genetic diseases in the Mendelian sense and anyway if you've had somebody paying insurers until they're eighty, you probably got a fair whack out of them."

Canadian Insurer

"[Most genetic test results are] such a poor prognosticator of whether somebody's gonna develop a disease or not that right now it just doesn't work. It doesn't work as well as the more commonly used [methods] whether it's urine test or blood test and so forth.

Australian Geneticist

“A concern for me… is that we do not know [insurers’] genetic literacy in calculating risk and we do not know whether they would be responsible with the usage of the genetic result in calculating risk and adjusting the policy.”

Actuarial Impact

THE IMPACT OF GENETIC INFORMATION ON THE INSURANCE INDUSTRY: CONCLUSIONS FROM THE 'BOTTOM-UP' MODELLING PROGRAMME

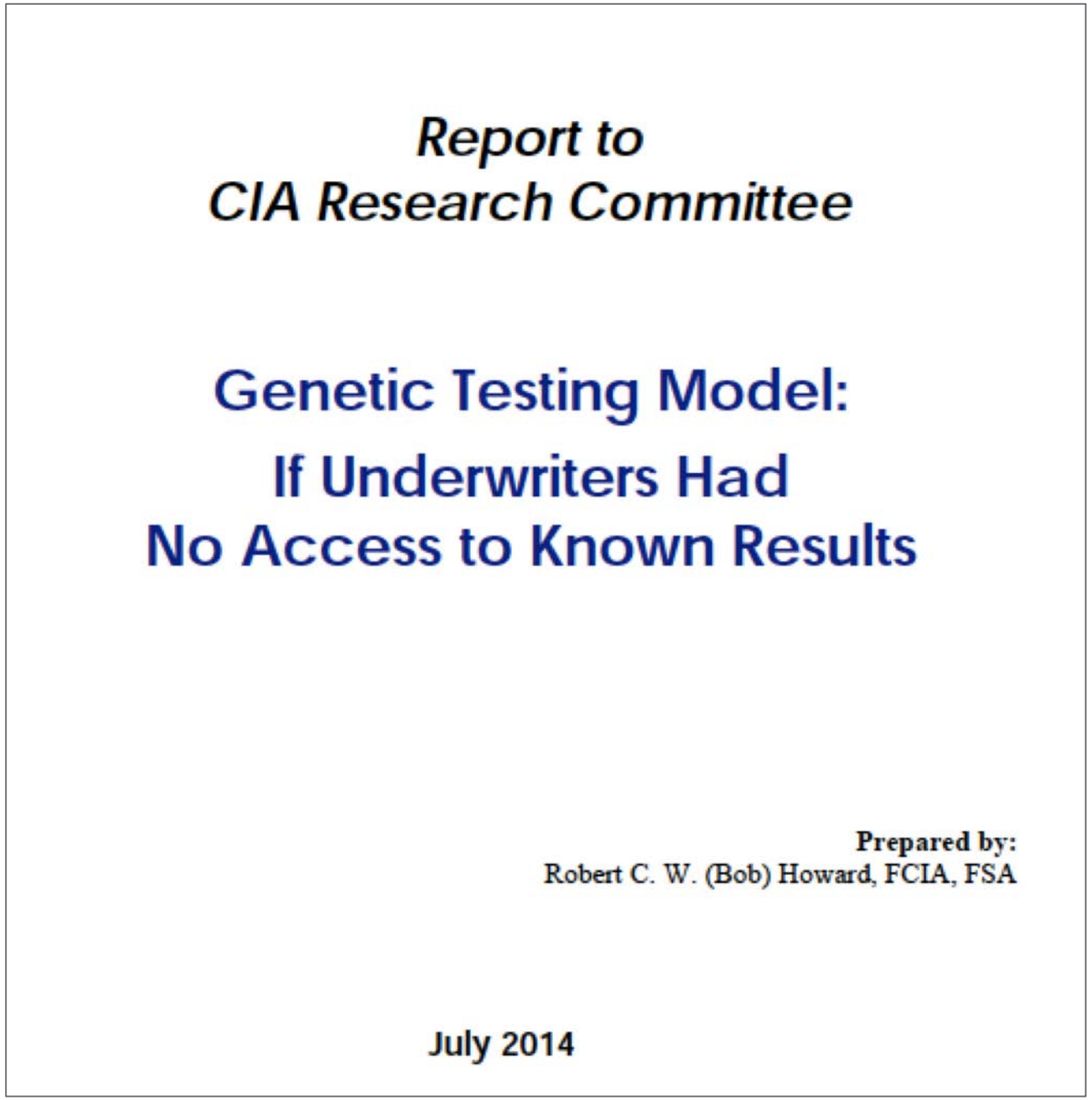
BY

ANGUS MACDONALD AND FEI YU

ABSTRACT

We quantify the overall impact of genetic information on the insurance industry using the 'bottom-up' approach, in which detailed models are constructed of representative major genetic disorders. We consider six such disorders, namely adult polycystic kidney disease, early-onset Alzheimer's disease, Huntington's disease, myotonic dystrophy (MD), hereditary non-polyposis colorectal cancer; and breast/ovarian cancer. Actuarial models based on the epidemiological literature exist for all these except MD. We parameterise a suitable model of MD, then synthesize the results from all six models to estimate the adverse selection costs arising from restrictions on insurers' use of genetic information. These are all very small, only in the most extreme cases rising above 1% of premiums. In the worst case — females displaying 'extreme' adverse selection in a 'small' critical illness insurance market, with the use of family history banned — the cost is about 3% of premiums. Our model includes the most common single gene disorders relevant to insurance, and includes representatives of most important classes of these disorders. While the 'bottom-up' approach could be continued by modelling more and more diseases, we suggest that our model is adequate to draw robust conclusions.

Angus Macdonald & Fei Yu, *The Impact of Genetic Information on the Insurance Industry: Conclusions from the 'Bottom-Up'modelling Programme*, 41 ASTIN BULLETIN (2011)



"I conclude that the impact on insurance companies will be substantial. The valuation strain (pricing loss) for the industry from those who test positive in a single year (based on the assumptions) would be about 12% of the total death claims for the year. The impact on consumers is likely to be even greater. As a result of the prohibition the average mortality rates are likely to increase by about 35% for males, and 60% for females in the age range 20–60; there would be a concomitant increase in term insurance premium rates."

- Where only the applicant knows the results of genetic testing but both the applicant and the insurance company know the family history at time of underwriting, future increases in expected new business claim cost range from 4% to 8% overall. When considering claims from the in-force block as well, industry-wide expected claim costs could rise by as much as 3%.

- Where only the applicant knows the result of genetic testing and family history, and the insurance company knows neither, future increases in expected new business claim cost range from 5% to 10% overall. When considering claims from the in-force block as well, industry-wide claim costs could rise by as much at 4%. Note that the relative impact of losing family history presented in this report is limited in that it only pertains to the 13 medical conditions modeled. Legislation limiting the use of family history in the underwriting process would affect the assessments of many medical impairments not considered specifically in this report; the true impact on claim cost will likely be greater.

The Impact of Genetic Testing on Life Insurance Mortality

October 2018

Assumptions – Insurance Purchasing Behavior

From the SOA Report:

The degree of the severity of the industry impact presented in this report is very sensitive to two assumptions:

1. the rate at which individuals in the general population get genetically tested and
2. the face amount purchased by individuals seeking insurance after finding they have genetic characteristics associated with an increased risk of developing a particular medical condition.

Both assumptions move the U.S. Model results proportionately, as shown in sensitivity tests 2 and 15 illustrated in Table 13 of Section 6. When we reduce both assumptions in combination,[1] the expected future claim increases are reduced by 75%.

Phases of insurers' debate

- I. Public Relations – public doesn't understand insurance principles
- II. Defensive Approach – dire economic impact
  - Adverse selection and right to underwrite
- III. Compromise position – rise of industry code
  - "science did not provide robust justification for insurers' ideological preference for implementing any technically feasible discrimination, and that politically negotiated solutions between that preference and wider social preferences were unavoidable"

Van Hoyweghen et al., 'Genetics Is Not the Issue': Insurers on Genetics and Life Insurance, 24NEW GENET. & SOC. 81 (2005)

Phases of insurers' debate

- IV. Continued saliency

Prince (2019)Political economy, stakeholder voices, and saliency: lessons from international policies regulating insurer use of genetic information

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