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The 2004 Healthcare Conference

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## Current Issues in Genetics Affecting Health Insurance

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## Background

- rapid advances in genetic knowledge
- may lead to increase in life expectancy
- and ability to treat wider range of conditions
- could permit more detailed risk classification
- …but this could undermine mutuality of risk
- or could threaten ability to underwrite at all

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## COUNCIL OF EUROPE

**Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (1997)**

Article 11 - prohibits any form of discrimination against a person on grounds of his or her genetic heritage

Article 12 - genetic testing may only be carried out for purposes of health care or research

- Convention not yet ratified by UK & some others

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## UK - Genetics & Insurance Committee (GAIC)

- advisory committee established by government
- separate from Human Genetics Commission(HGC)
- GAIC invites proposals from insurance industry
- seeks clinical and actuarial evidence of test validity
- tests can be approved for specific applications
- may impose conditions on use of tests

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## Is GAIC process sensible?

- provides incentive for research…
- …leading to better understanding of issues
- provides disciplined framework for debate
- is standard of proof high enough?
- insurers not required to demonstrate damage

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## The ABI Moratorium (November 2001 to November 2006)

- genetic tests will not be requested by insurers
- genetic information will be ignored for life insurance business up to £500K
- £300K for CI; £30K a year for IP
- otherwise insurers expect disclosure of results of agreed tests which have already been carried out
- ABI agrees to submit tests to GAIC for approval

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## GAIC – the story so far

- consultation on process for approving tests
- first submission - September 2000...
- ...Huntington's Disease for life insurance
  - approved October 2000
- 17 further submissions - end December 2000
  - Huntington's Disease – CI, IP, LTC
  - breast cancer (BRCA1 and BRCA2)
  - EO Alzheimer's Disease (PS1 and APP)
- GAIC re-established in 2002 with new members and new approach (first meeting Sept. 2002)

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## GAIC – criteria for assessing applications for the use of genetic tests in setting insurance premiums

- Technical relevance: does the test accurately measure genetic information?
- Clinical relevance: does a positive result in the test have likely future adverse implications for the health of the individual?
- Actuarial relevance: does a positive result justify increased premiums?

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## Actuarial relevance - 1

*Answers to be no more than 20 pgs (~10000 words)*

- Quantify the extra risk justifying need to increase premiums or decline applications
- Show consistency with relevant research
- Describe method for calculating premiums and range about the best estimate
- Show how test results may affect ratio of people accepted and compare with family history alone

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## Actuarial relevance - 2

- Describe recent advances in treatment or prevention options that might change mortality or morbidity risk and how such factors have been taken into account
- Include short draft guidelines about the likely impact on consumers
  a) to help insurance companies better determine a fair underwriting approach; and
  b) to help consumers better understand the underwriting approach

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## GAIC discussions with "ABI actuaries"

- "actuarial workshop" in December 2003
- standard technique should be multi-state models
- model for determining "actuarial relevance" should also be relevant as an underwriting tool
- results should be presented as a matrix to show where there are age/term combinations for which above standard rating is justified

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## UK Forum for Genetics & Insurance (UKFGI) (est. 1998)

- broad membership
- aims to encourage dialogue
- mutual education,
  e.g. geneticists and underwriters
- public information
- forum to present new research
- can be consulted by GAIC

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## Research so far

- Smith (Swiss Re) Huntington's Chorea
- Macdonald *et al* (Heriot-Watt)
  - breast and ovarian cancer
  - Adult Polycystic Kidney Disease
  - Alzheimer's Disease
  - impact of moratorium on family history
- Lemaire/Subramanian – breast/ovarian cancer
- Pokorski/Ohlmer – BRCA1/2 and LTC

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## The cost of genetic information

- If insurers do have genetic information:
  - people at higher risk might pay more
  - how much more would they need to pay?
- If insurers do not have genetic information
  - people at higher risk might over-insure
  - how much would that cost everyone else?
- answers require actuarial models/research

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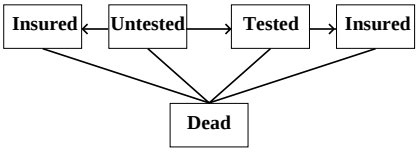
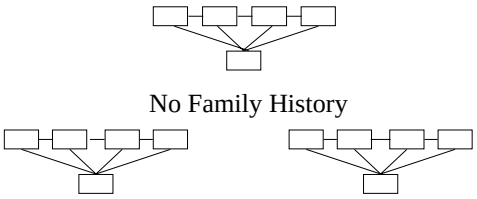
## A simple life insurance model






## No moratorium



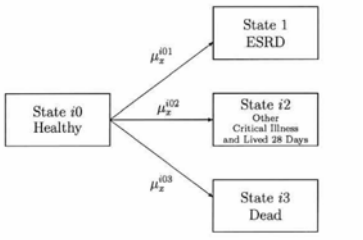
No Family History

Family History
No Mutation

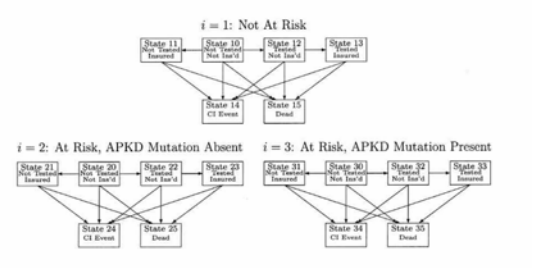
Family History
Mutation



A model for APKD and CI insurance, in the $i^{th}$ of several subpopulations representing genotype



Markov model of critical illness insurance allowing for family history of APKD and genetic testing






## Features of the model

- the "normal" level of insurance
- the extent of genetic testing
- the probability of a positive result
- the behaviour of "adverse selectors"
- the behaviour of insurers
- the impact of family history information
- transition between states



## Early conclusions - 1

- Huntington's Disease is clear-cut…
- …and is usually known from family history
- monogenic conditions are rare…
- …so impact of ignoring them might be slight
- penetrance of many genes is overstated…
- …because of nature of research studies

## Early conclusions - 2

- selection against the insurer may be a problem
  - if over-insurance is allowed
  - if markets are small
  - particularly for critical illness and LTC
- without adverse selection impact is modest
- loss of family history might be more serious
- multifactorial conditions unlikely to matter

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## Products most affected

- life insurance (protection products)
- critical illness / dread disease
- long-term care
- private medical insurance
- annuities?

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## A way forward?

- insurers will not request genetic tests…and will ignore known results of tests except for large amounts…
- ...for which prior test results should be disclosed
- provide evidence of significance of tests/vulnerability
- accelerate research (actuarial as well as genetic)
- translate research into sound actuarial models
- encourage all underwriting to be more based on scientific evidence

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## Genetics and Insurance – some social policy issues

by Chris Daykin, Debbie Akers, Angus Macdonald, Tony McGleenan, David Paul and Peter Turvey

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