



Centre for Biomedical Ethics  
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# From Pragmatism to Justice: Rethinking Genetic Discrimination Laws

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# BRIEF BACKGROUND ON GENETIC DISCRIMINATION



- Longstanding ethical pitfall of genetic testing: genetic discrimination
- Genetic testing → Info on genetic disease and/or predisposition
  - Insurance premiums/insurance coverage
  - Employment
  - Personal relationships

# CURRENT PROJECT: LIFE INSURANCE FOCUS



- More manageable for comparative analysis
- Important area for individual practice and regulation
- Subject to significant policy interventions globally
  - Exception: GINA in the US, doesn't cover life insurance

# INTERNATIONAL COMPARISON



- Several existing international surveys (see, e.g., Global Observatory: <https://gdo.global/> )
- But need deeper analysis of normative underpinnings to properly evaluate policy
  - 1) What are the purported ethical justifications for GD protections?
  - 2) Are those justifications adequate?
- Limited to 6 countries: UK, SG, Aus, NZ, Japan, S. Korea
  - Asian + Western coverage
  - More manageable for deeper ethical analysis

# A TALE OF TWO JUSTIFICATIONS



Justice



Pragmatism

# COMPARISON RESULTS, PT 1



Country	Regulatory Approach	Justification	Predictive (exceptions)	Diagnostic (exceptions)	Voluntary Submission	Family History
UK	Moratorium (2001-) Government & ABI	Pragmatic "To promote uptake of tests."	● (financial threshold Huntington's Disease)	●	●	●
Singapore	Moratorium (2021-) MOH & LIA	Pragmatic "To avoid deterring people from tests."	● (financial threshold + Huntington's Disease  BRCA1/2  Familial Hypercholesterolemia)	●  (Familial Hypercholesterolemia)	●	●
Australia	Moratorium (2019-), Prospective Law (2024-)	Pragmatic "To promote access and remove barriers to testing."	● (current financial threshold, law will abolish)	● (current financial threshold, law will abolish)	● (only if doesn't adversely affect applicant)	●

# COMPARISON RESULTS, PT 2



Country	Regulatory Approach	Justification	Predictive (exceptions)	Diagnostic (exceptions)	Voluntary Submission	Family History
Canada	Federal Legislation (Genetic Non-Discrimination Act, 2017)	Pragmatic + Justice "Combat GD and preserve autonomy in testing."	●	●	●	●
Korea	National Legislation (Bioethics and Safety Act, 2008)	Unclear "To uphold dignity, health, and safety; bans genetic discrimination in all social domains."	Unclear	Unclear	Unclear	●
Japan	Law (Genome Medicine Promotion Act, 2023) & Self-Reg (LIAJ, 2022)	Justice +Pragmatic "To prevent unjust discrimination and promote responsible genomic medicine."	●	●	●	●

# JUSTICE-BASED JUSTIFICATIONS



- Basic idea: it is *unfair* to genetically discriminate
  - Genetic traits unchosen/outside control → disadvantage through no fault of own
  - Insurance as important good to fairly distribute
- More prevalent in ethics literature, less in regulatory space
- Implication: Bar insurance use of BOTH genetic test AND family history
  - Family history + genetic test results share ethically salient similarities: unchosen/outside control (indeed, family history an indirect proxy for some genetics)

# PRAGMATIC JUSTIFICATIONS



- Basic idea: discrimination disincentivizes testing
  - Testing an important social good (improve care/prevent disease)
  - → Policy aim to bar discrimination to increase testing uptake
- Dominant in surveyed jurisdictions (exception: Japan)
- Implication: Bar insurance use of genetic testing, allow family history
  - Pragmatic concerns about disincentive only apply to testing (no worry about barriers to learning family history)

# WHICH IS ETHICALLY STRONGER?

- Justice-based frameworks have more solid, defensible normative basis
  - Intrinsic wrongness of discrimination is not contingent
  - (though need to be weighed against adverse impact on markets)
- Contrast: Pragmatism contingent on uncertain empirical questions
  - Do anti-GD laws/regs \*really\* improve uptake?
  - Current evidence lacking → weak justification for substantial regulatory interference in private transactions

# UPSHOT: BE MORE LIKE JAPAN!



- Japan has comprehensive restrictions, across both testing and family history w/solid justifications
  - Long-standing practice, hasn't led to insurance market collapse
- Justice-based frameworks can advance fairness, while (speculatively) still potentially reaping pragmatic benefits
  - E.g., comparative survey of SG vs Japan: 3% experienced GD in Japan vs 20% in SG (Takahashi et al., "Addressing Genetic Discrimination for Stronger Legal Protections and Enhanced Public Awareness" NPJ Genomic Medicine, in press)
  - Side-note: GINA in the US also covers family history, but has serious limitations including life insurance exclusion
  - Don't be like the US (rule of thumb)

# THANK YOU