The Risk of a Personalized Insurance Industry

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The Purpose of Insurance

Insurance is designed to mitigate risk

- Spreads the chance of an accident among a broad population
- Also spreads the expense of care

Rates are set for general groups

- By employer, by large demographic groups

Exists for many industries, including health, property, automobile, etc.

Data Enters the Car Insurance Industry

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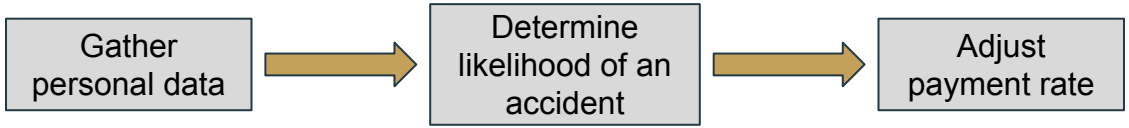

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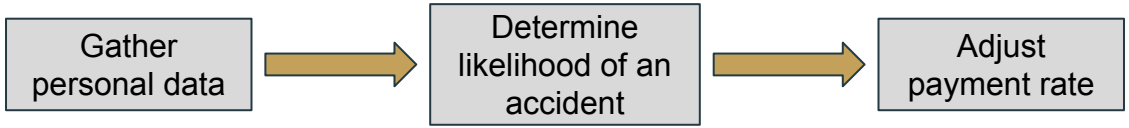
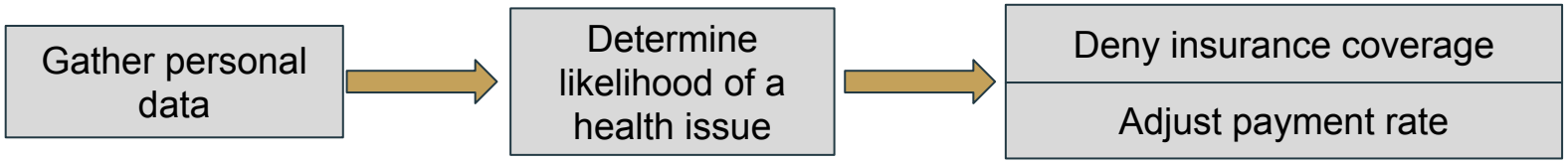


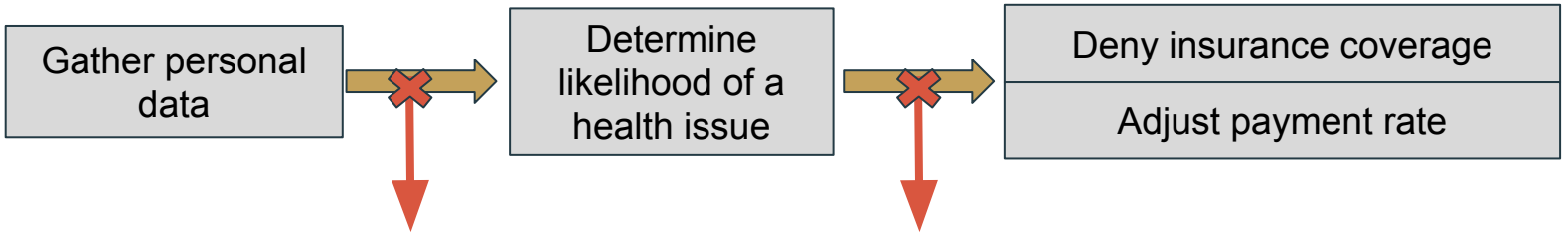
These programs are generally accepted by customers

- Opt-in
- Not deeply personal information
- In driver's control (and everyone thinks they're a good driver…)

Apply This Model to Medical Insurance?



Medical Insurance Is Protected by Law

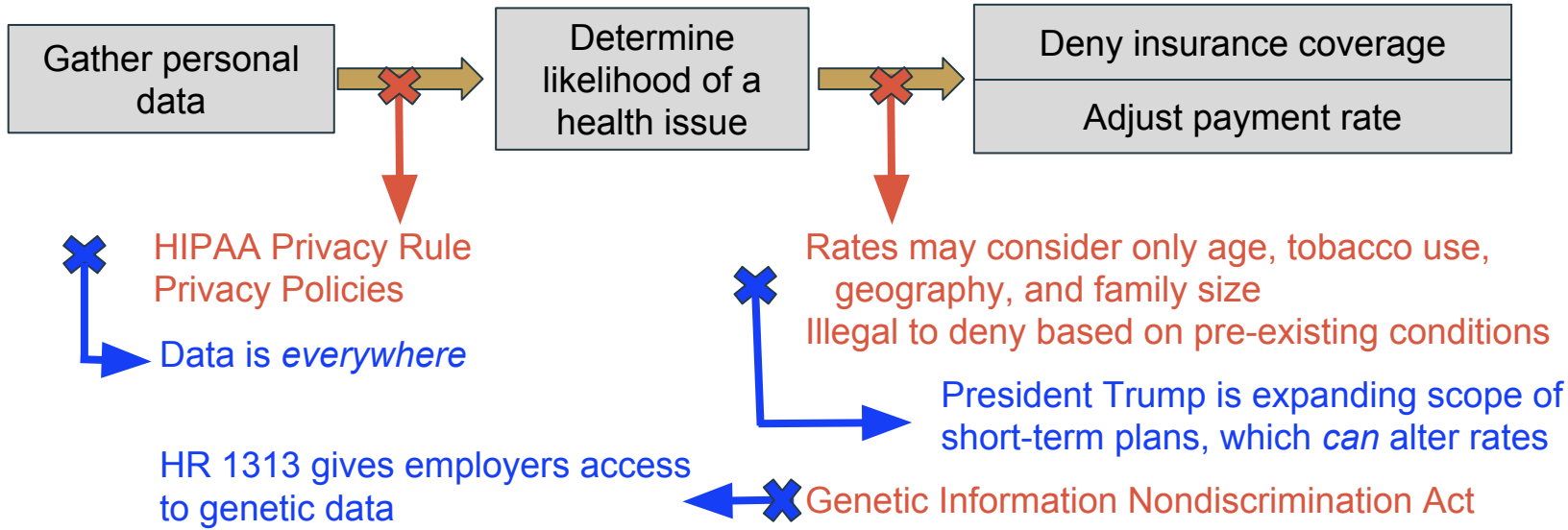


HIPAA Privacy Rule
Privacy Policies

Rates may consider only age, tobacco use, geography, and family size
Illegal to deny based on pre-existing conditions

Genetic Information Nondiscrimination Act

Or Is It...?


Gather personal data
Determine likelihood of a health issue
Deny insurance coverage
Adjust payment rate
HIPAA Privacy Rule
Privacy Policies
Data is *everywhere*
Rates may consider only age, tobacco use, geography, and family size
Illegal to deny based on pre-existing conditions
President Trump is expanding scope of short-term plans, which *can* alter rates
HR 1313 gives employers access to genetic data
Genetic Information Nondiscrimination Act

Insurers Are Turning to Data

Fitness band tracking data - discounts and incentives for hitting step goals

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- Plus-size clothing purchases → dietary services or cardiac care

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Extrapolation from "non-medical" data - predicting health risk from obscure factors

- Type of car owned, investments, neighborhood, relatives living in the area, etc
- These factors are less directly linked to outcomes, but also less shielded by law

What's Next? Social Media

Sentiment analysis of Tweets - more optimistic tweeters have reduced risk of heart disease

Swiss Re is incorporating this information into insurance rates

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Life events - pregnancy, travel, work stress...

Hobbies - running marathons, drinking...

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Account creation

Different platforms tend towards different demographics, hobbies, priorities, and mental states

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Contextual Integrity:

"...locate contexts, explicate entrenched informational norms, evaluate disruptive flows, and evaluate these flows against norms based on general ethical and political principles as well as context-specific purposes and values."

What's Next? Other Web Data

Alexa home recordings

Habits, movement patterns, search requests - all potentially predictive of health

Food Diary App Data

Nutrition and weight information - *certainly* related to health outcomes

Amazon purchases

Magazine subscriptions

Website visits and articles read

Indicate hobbies and interests

Not concretely linked to health outcomes,

but certainly correlated

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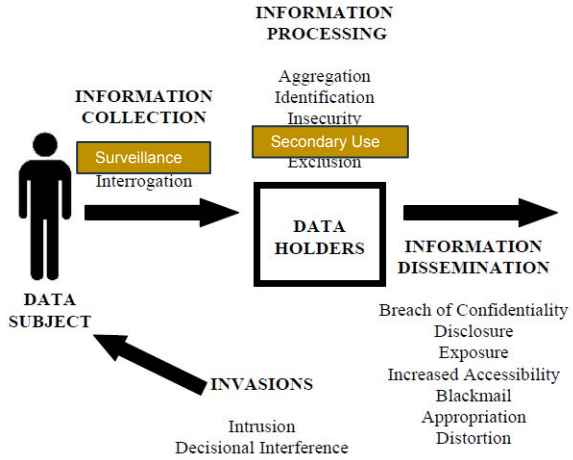

What's Next? DNA

DNA testing services (23andMe) - Ancestry & Health Reports

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5+ reports

Genetic Health Risk reports*

BRCA1/BRCA2 (Selected Variants)
Learn more
Genetic risk based on a limited set of variants for breast, ovarian and other cancers
3 variants in the BRCA1 and BRCA2 genes; relevant for Ashkenazi Jewish descent

Age-Related Macular Degeneration
Genetic risk for a form of adult-onset vision loss
2 variants in the ARMS2 and CFH genes; relevant for European descent

Alpha-1 Antitrypsin Deficiency
Genetic risk for lung and liver disease
2 variants in the SERPINA1 gene; relevant for European descent

Celiac Disease
Genetic risk for gluten-related autoimmune disorder
2 variants near the HLA-DQB1 and HLA-DQA1 genes; relevant for European descent

G6PD Deficiency
Genetic risk for a form of anemia
1 variant in the G6PD gene; relevant for African descent

Hereditary Hemochromatosis (HFE-Related)
Genetic risk for iron overload
2 variants in the HFE gene; relevant for European descent

Hereditary Thrombophilia
Genetic risk for harmful blood clots
2 variants in the F2 and F5 genes; relevant for European descent

Late-Onset Alzheimer's Disease
Genetic risk for a form of dementia
1 variant in the APOE gene; variant found and studied in many ethnicities

Parkinson's Disease
Genetic risk for a form of movement impairment
2 variants in the LRRK2 and GBA genes; relevant for European, Ashkenazi Jewish, North African Berber descent

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5+ reports

Genetic Health Risk reports*

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Wellness reports

Alcohol Flush Reaction
Caffeine Consumption
Deep Sleep
Genetic Weight
Lactose Intolerance
Muscle Composition
Saturated Fat and Weight
Sleep Movement

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Genetic Health Risk reports*

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Wellness reports

25+ traits

Traits reports

Ability to Match Musical Pitch
Asparagus Odor Detection
Back Hair (available for men only)
Bald Spot (available for men only)
Bitter Taste
Cheek Dimples
Cilantro Taste Aversion
Cleft Chin
Earlobe Type
Early Hair Loss (available for men only)
Earwax Type
Eye Color
Fear of Heights
Finger Length Ratio
Freckles
Hair Photobleaching (hair lightening from the sun)
Hair Texture
Hair Thickness
Light or Dark Hair
Misophonia (hatred of the sound of chewing)
Mosquito Bite Frequency
Newborn Hair
Photic Sneeze Reflex
Red Hair
Skin Pigmentation
Sweet vs. Salty
Toe Length Ratio
Unibrow
Wake-Up Time
Widow's Peak

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5+ reports

Genetic Health Risk reports*

5+ reports

Wellness reports

25+ traits

Traits reports

40+ reports

Carrier Status reports*

ARSACS
1 variant in the SACS gene; relevant for French Canadian descent

Agenesis of the Corpus Callosum with Peripheral Neuropathy
1 variant in the SLC12A6 gene; relevant for French Canadian descent

Autosomal Recessive Polycystic Kidney Disease
3 variants in the PKHD1 gene

Beta Thalassemia and Related Hemoglobinopathies
10 variants in the HBB gene; relevant for Sardinian, Cypriot, Italian/Sicilian, Greek descent

Bloom Syndrome
1 variant in the BLM gene; relevant for Ashkenazi Jewish descent

Canavan Disease
3 variants in the ASPA gene; relevant for Ashkenazi Jewish descent

Congenital Disorder of Glycosylation Type 1a (PMM2-CDG)
2 variants in the PMM2 gene; relevant for Danish descent

Cystic Fibrosis
29 variants in the CFTR gene; relevant for Ashkenazi Jewish, European, Hispanic/Latino descent

D-Bifunctional Protein Deficiency
2 variants in the HSD17B4 gene

Dihydrolipoamide Dehydrogenase Deficiency
1 variant in the DLD gene; relevant for Ashkenazi Jewish descent

Familial Dysautonomia
1 variant in the IKBKAP gene; relevant for Ashkenazi Jewish descent

Familial Hyperinsulinism (ABCC8-Related)
3 variants in the ABCC8 gene; relevant for Ashkenazi Jewish descent

Fanconi Anemia Group C
3 variants in the FANCC gene; relevant for Ashkenazi Jewish descent

GRACILE Syndrome
1 variant in the BCS1L gene; relevant for Finnish descent

Gaucher Disease Type 1
3 variants in the GBA gene; relevant for Ashkenazi Jewish descent

Glycogen Storage Disease Type Ia
1 variant in the G6PC gene; relevant for Ashkenazi Jewish descent

Glycogen Storage Disease Type Ib
2 variants in the SLC37A4 gene

Hereditary Fructose Intolerance
4 variants in the ALDOB gene; relevant for European descent

Herlitz Junctional Epidermolysis Bullosa (LAMB3-Related)
3 variants in the LAMB3 gene

Leigh Syndrome, French Canadian Type
1 variant in the LRPPRC gene; relevant for French Canadian descent

Limb-Girdle Muscular Dystrophy Type 2D
1 variant in the SGCA gene

Limb-Girdle Muscular Dystrophy Type 2E
1 variant in the SGCB gene; relevant for Amish descent

Limb-Girdle Muscular Dystrophy Type 2I
1 variant in the FKRP gene

MCAD Deficiency
4 variants in the ACADM gene; relevant for European descent

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The 23andMe PGS test uses qualitative genotyping to detect select clinically relevant variants in the genomic DNA of adults from saliva for the purpose of reporting and interpreting genetic health risks and reporting carrier status. It is not intended to diagnose any disease. Your ethnicity may affect the relevance of each report and how your genetic health risk results are interpreted. Each genetic health risk report describes if a person has variants associated with a higher risk of developing a disease, but does not describe a person's overall risk of developing the disease. The test is not intended to tell you anything about your current state of health, or to be used to make medical decisions, including whether or not you should take a medication, how much of a medication you should take, or determine any treatment. Our carrier status reports can be used to determine carrier status, but cannot determine if you have two copies of any genetic variant. These carrier reports are not intended to tell you anything about your risk for developing a disease in the future, the health of your fetus, or your newborn child's risk of developing a particular disease later in life. For certain conditions, we provide a single report that includes information on both carrier status and genetic health risk. **Warnings & Limitations: The 23andMe PGS Genetic Health Risk Report for BRCA1/BRCA2 (Selected Variants) is indicated for reporting of the 185delAG and 5382insC variants in the BRCA1 gene and the 6174delT variant in the BRCA2 gene. The report describes if a woman is at increased risk of developing breast and ovarian cancer, and if a man is at increased risk of developing breast cancer or may be at increased risk of developing prostate cancer. The three variants included in this report are most common in people of Ashkenazi Jewish descent and do not represent the majority of BRCA1/BRCA2 variants in the general population. This report does not include variants in other genes linked to hereditary cancers and the absence of variants included in this report does not rule out the presence of other genetic variants that may impact cancer risk. The PGS test is not a substitute for visits to a healthcare professional for recommended screenings or appropriate follow-up. Results should be confirmed in a clinical setting before taking any medical action. For important information and limitations regarding each genetic health risk and carrier status report, visit 23andme.com/test-info/*

but the caveat is in small print, and customers certainly extrapolate!

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→ Insurers may begin over-pricing services, then offering "rewards" to those that share

Not technically penalizing those that don't share

→ DNA information and health survey answers reflect relatives' data

The submitter doesn't have a right to breach their privacy

DNA Shared Without Consent

Companies are purchasing access to 23andMe's database

- GlaxoSmithKline, Pfizer, Genentech - supposedly for drug design
- Partnerships with 14 large-scale health industry companies
  - *"Wojcicki says she envisions a time when 23andMe can allow virtually anybody to run queries on its huge store of genetic information using a web portal. 'Need to find out of there's a possibility of asthma in this cohort? Just push a button,' she said."*

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Privacy Policy takes little care over data sharing across companies

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What about a security breach??

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Over-personalization negates the purpose of insurance

- If rates are customized to each individual, the risk/expense-sharing concept is broken
- Borders on discrimination

Recommendations & Warnings

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Laws must stay ahead of data generation - but that is no easy task

- Regulations must be made to protect the *intent* of insurance
- Prohibit discrimination and coercion in any form
  - rather than trying to anticipate specific pieces of data that may be harmful