

Big Data and Legal Barriers to Scientific Discovery: Patient & Data Owner Interactions

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Culture Change

- permissioning data: a culture change from privacy protection
 - donating genomic data to databases,
 - risks,
 - facilitation.
- informed consent for complex discovery.
 - changing definition; an outdated model?

(Self) Assessment Tests

 NATIONAL CHOLESTEROL EDUCATION PROGRAM
Third Report of the Expert Panel on
Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults (Adult Treatment Panel III)

Risk Assessment Tool for Estimating Your 10-year Risk of Having a Heart Attack

The risk assessment tool below uses information from the Framingham Heart Study to predict a person's chance of having a heart attack in the next 10 years. This tool is designed for adults aged 20 and older who do not have heart disease or diabetes. To find your risk score, enter your information in the calculator below.

Age: years

Gender: Female Male

[Total Cholesterol:](#) mg/dL

[HDL Cholesterol:](#) mg/dL

[Smoker:](#) No Yes

[Systolic Blood Pressure:](#) mm/Hg

Are you currently on any medication to treat high blood pressure. No Yes

- big data platforms for large scale test validation (ie. heart disease risk assessment, stroke risk, etc <http://hp2010.nhlbi.nih.net/atpiii/calculator.asp>)
- downstream acceptance: implementing recommendations for breast cancer and other provider based tests.

Driver: Data Availability

- legal templates, health care system reforms, technological insertion, legal reform (FDA requirements on validation data vs trade secrets), education (ie <http://weconsent.us>), ...
- examples and prototypes that are around today? community standards for sharing, protocols, ...
- rewarding information sharing: returning results, examples of impact, ...

Data Donors

- Central repository for (identified) patient data,
 - points / award levels for sharing / citation
 - identification of potential donors
 - permissioning claims data
 - shielding patient genomic data / anonymization technics
 - integration of clinical trials of I