Data Governance and Access: International Perspective

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Outline

Disclosure:

- Co-lead GA4GH Regulatory and Ethics Work Stream (REWS), GA4GH
- Director (PI), Genetic Discrimination Observatory (GDO)

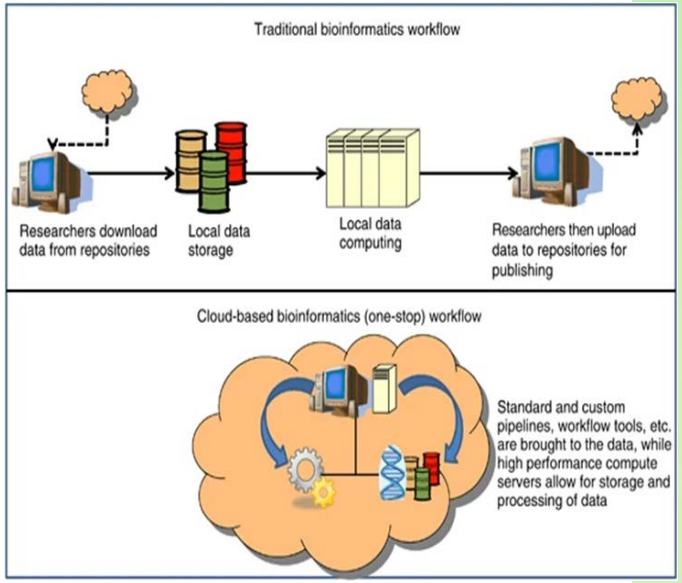
Digital health applications and the need for global governance

Global Alliance for Genomics and Health (GA4GH)

Genome Discrimination Observatory (GDO)

Digital health applications and the need for global governance

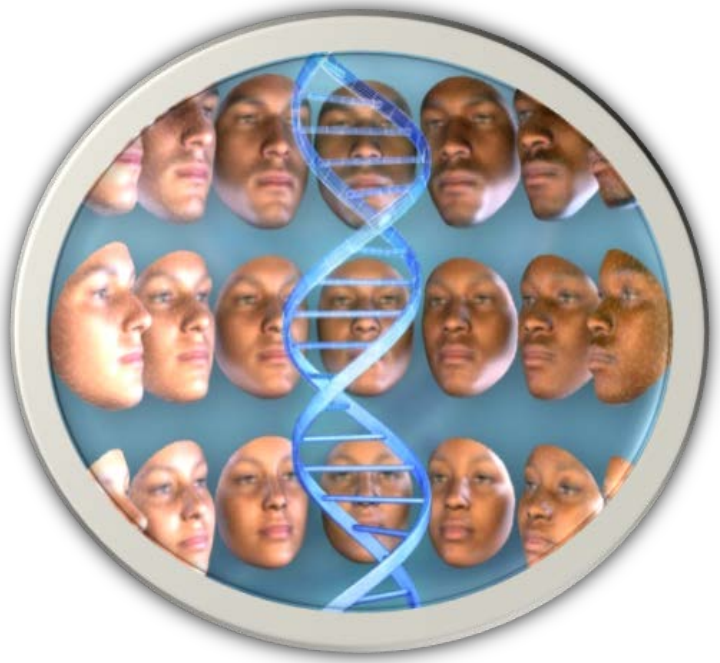
- Data intensive applications require vast quantity of data to train algorithms, identify interesting correlations, validate findings, etc.
- International collaborations offer new hope to resolve challenges of rare cancer subtypes
- Cancer initiatives have gotten increasingly international in nature. For exemple, the ICGC 25K (2007-2017), created a genetic database that comprises genetic and health data from 17,000 cancer patients from 76 research projects in 17 countries.
- Advent of cloud computing using geographically dispersed data centers



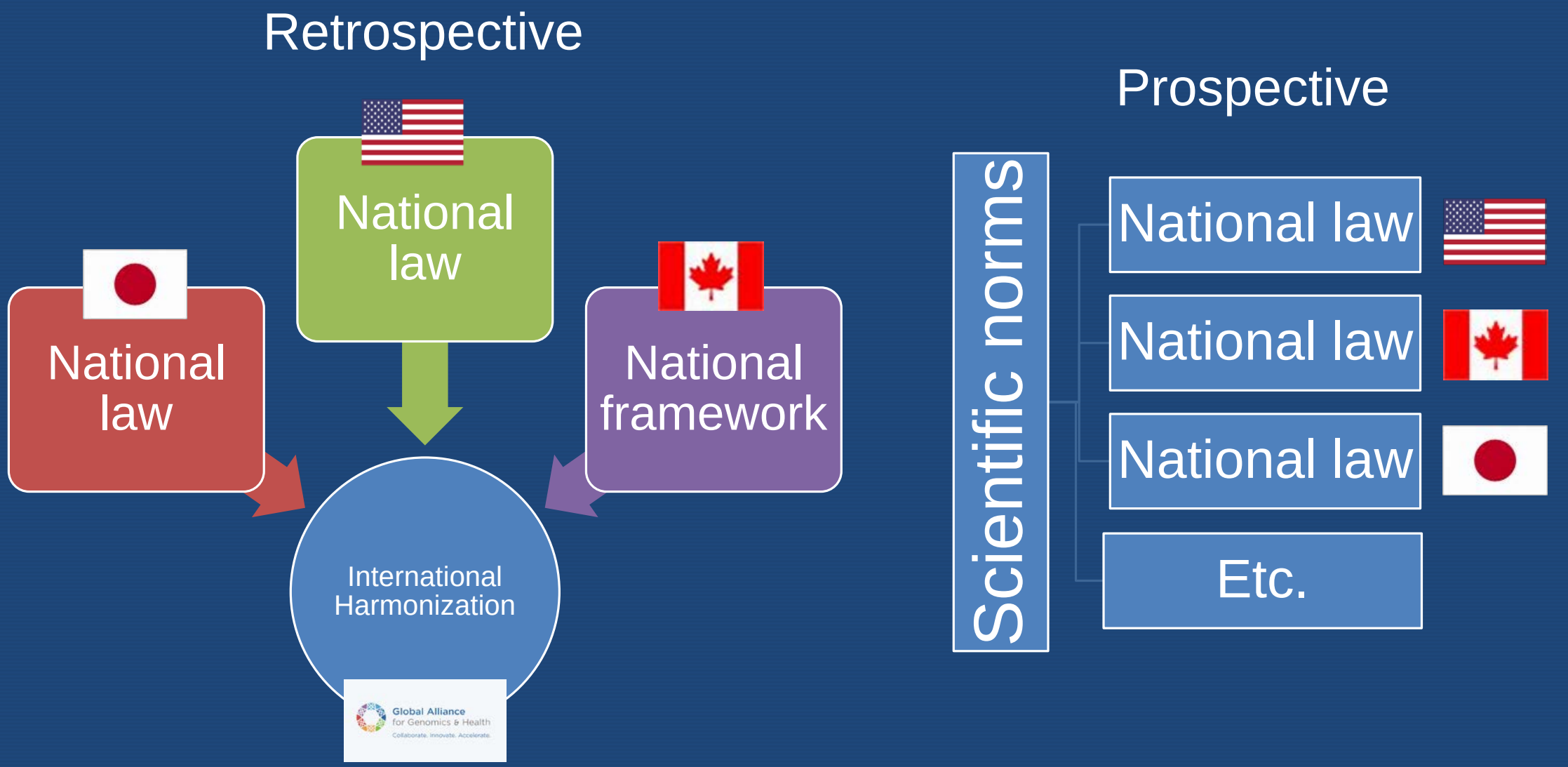
Digital health applications and the need for global governance

Coherence and predictibility!

- Incentive- rewards
- Data protection
- Ethics approval
- Liability and exclusions
- Regulatory approval

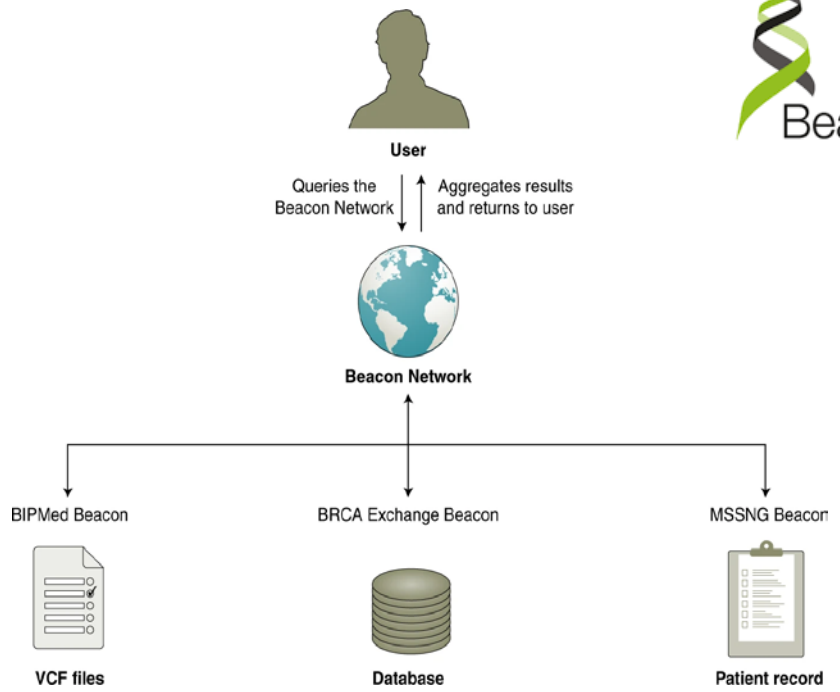


Digital health applications and the need for global governance



Global Alliance for Genomics and Health (GA4GH)

- The Beacon Project
- The BRCA Challenge
- Guidelines and standards



Fiume M. et al. Nature Biotechnology, (37) 2019

Global Alliance for Genomics & Health

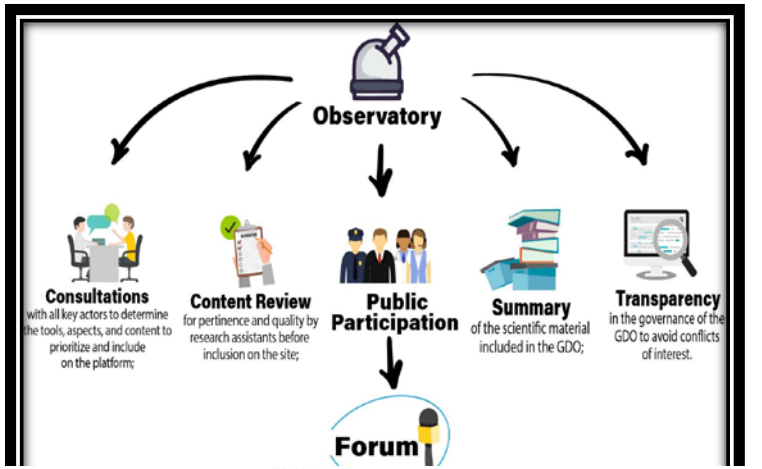
Collaborate. Innovate. Accelerate.

The Genetic Discrimination Observatory (GDO)

- The Genetic Discrimination Observatory (GDO) is a unique network of researchers and other stakeholders dedicated to researching and preventing discrimination based on genomic and other predictive health data worldwide

Tools:

- Report a case (direct to participant features that enables the reporting of genetic discrimination incidents)
- World views (international meta analysis of data on GD, regularly updated by local experts)



GD

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