Rethinking Health Data Ownership in the Era of Digital Health

Amalio Telenti, MD PhD
Dept. of Integrative Structural and Computational Biology
The Scripps Research Institute
La Jolla, California

Chief data scientist – Vir Biotechnology
San Francisco, California
Advisory boards:
- nFerence Inc.
- Caris Life Sciences
- Bitmark Inc.

Employment:
- Vir Biotechnology

This presentation is prepared by me in my personal capacity.
The views and opinions expressed in this presentation are mine and do not necessarily reflect the official policy or position of Vir Biotechnology, or any other individual, employee, agency, organization, or company associated with Vir Biotechnology.

Any content provided by me is my own opinion.
Points of discussion

• There is a lot of health data being created
• The rise of alternative models in the data market
• Risks and solutions for data protection

>>> Data ownership my lead to disruption in health care
Medicine as Data Sciences

Health systems will generate >2000 EB of data by year 2020

*McKinsey 2019*
European '1+ Million Genomes' Initiative 2022

EU countries agreed to cooperate in linking genomic data across borders

THEY DID IT! & more will too

Austria
Bulgaria
Croatia
Cyprus
Czech Republic
Estonia
Finland
Greece
Hungary
Italy
Latvia
Lithuania
Luxembourg
Malta
Netherlands
Norway
Portugal
Slovenia
Spain
Sweden
UK
• Integration of genome-based knowledge and technologies into public health research, policy and practice (PHG)
• HNA (Health Needs Assessment), HTA (Health Technology Assessment), HIA (Health Impact Assessment) and PIA (Policy Impact Assessment)
• Knowledge base for evidence-based policy-making
• Interdisciplinary and inter-institutional research and training
• UK Biobank is a source of resources for biomedical research open to accredited British and international researchers
• Data on health and wellbeing for 500,000 “unidentified” volunteers.
• Clinical, genetic, imaging and biomarker data
• 802 publications in 7 years
Zenome, CoverUS, LunaDNA, Doc.ai, Medicalchain, Proof Work, Nebula Genomics

Data brokers

Institutions

Cohorts

Industry

Health records

Owner

Health Data

Telenti et al. Lancet, March 2018
Mayo Clinic taps Google for analytics, innovation, cloud computing

Andrea Park - 24 hours ago Print I Email

Mayo Clinic announced a 10-year strategic partnership with Google, which will provide the Rochester, Minn.-based health system with technological support to advance digital healthcare innovation.
Data brokers

Zenome, CoverUS, LunaDNA, Doc.ai, Medicalchain, Proof Work, Nebula Genomics

Institutions

Cohorts

Industry

Comoditized Health records

Health Data

Owner

Telenti et al. Lancet, March 2018
Medical history on the phone

https://support.apple.com/en-us/HT208647
Number of mHealth apps available in the Apple App Store from 1st quarter 2015 to 3rd quarter 2019

Blockchain contracts

Alice

- Creates
- Issues
- Transfers Bitmark #1
  - Bitmark Certificate Issuance
  - Disabled

Bob

- Signs

Match Service
  - Request Consent for Trial Match
  - Respond with Consent
  - Health Data Sent

Candidate
  - Candidate Consents?
    - YES
    - NO
  - Evaluation Positive
    - Candidate Consents to Enrollment Invitation
    - Candidate Not Invited to Enroll
      - Health Data Returned to Candidate
  - Bitmark Certificate
  - Bitmark Certificate
  - Bitmark Certificate

Sponsor
  - Sponsor Evaluates Candidate or Study
    - YES
    - NO

Inform of Successful Match

Health Data sent for Sponsor

Health Data sent

YES

NO

Candidate?

Trial Asset

Asset

Candidate?

Evaluation

Positive

Candidate?

Response for Enrollment

Invitation
Spread of genetic information via social media

Risks

Telenti F1000Research 2014
**Solutions**

**Sandbagging:** Instead of the data going away for analysis, the algorithm comes to the institution.

**Homomorphic encryption**

---

**Genetics in Medicine** volume 18, pages 814–822 (201

**Edge AI:** AI processing today is mostly done in a cloud-based data center with deep learning models that require heavy compute capacity. However, with Edge AI, AI processing is now moving part of the AI workflow to a device.
• The concept of data ownership needs to be considered for its potential for profound disruption.

• Effectively, it translates in health data transferring outside the Institutions.

• Privacy, exchange, contracts, ethics, risks and the specific role of health systems need to be reexamined under such alternative model.