

Rethinking Health Data Ownership in the Era of Digital Health

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A WORLD WITHOUT INFECTIOUS DISEASE

COI

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- nFference Inc.
- Caris Life Sciences
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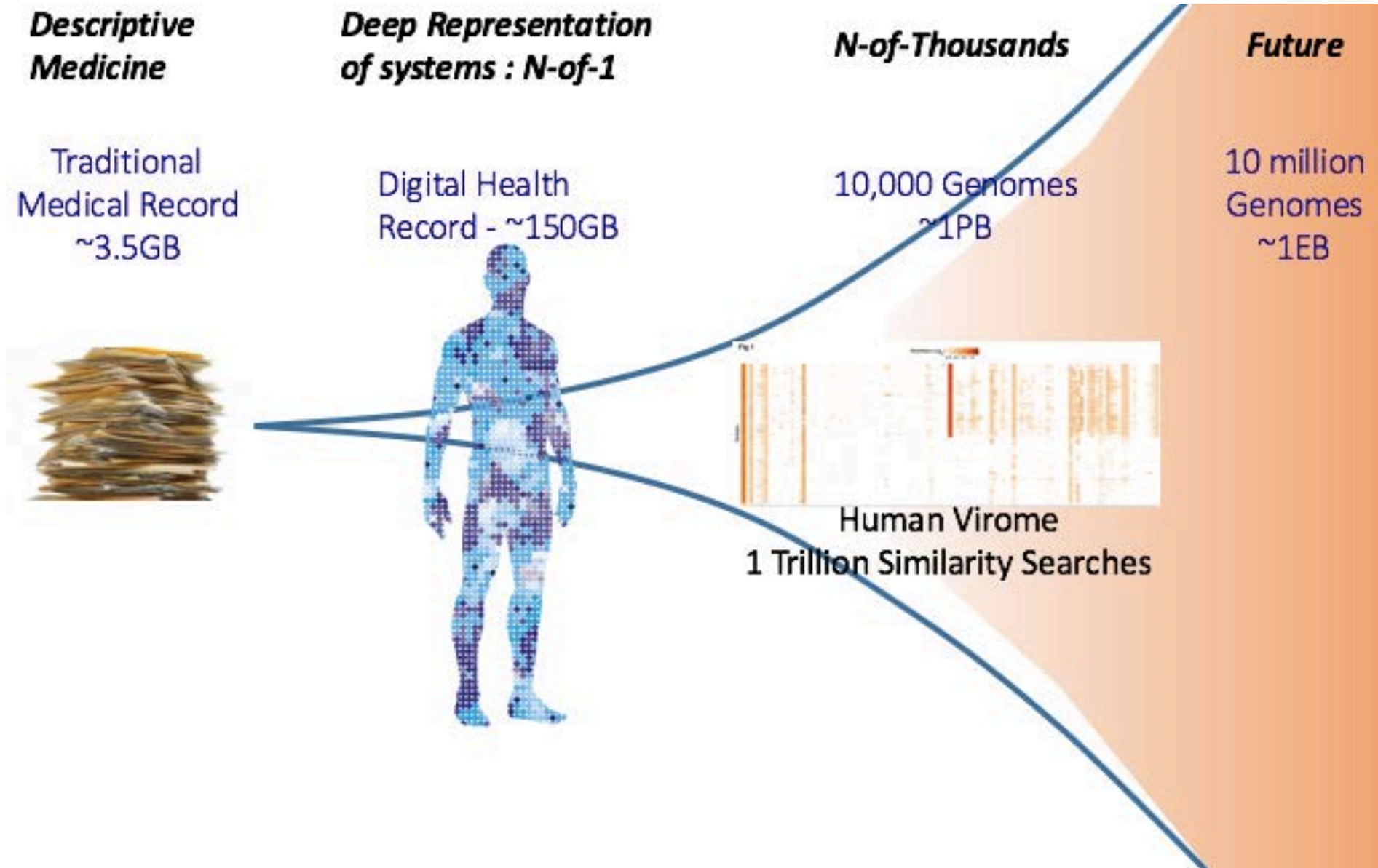
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Points of discussion

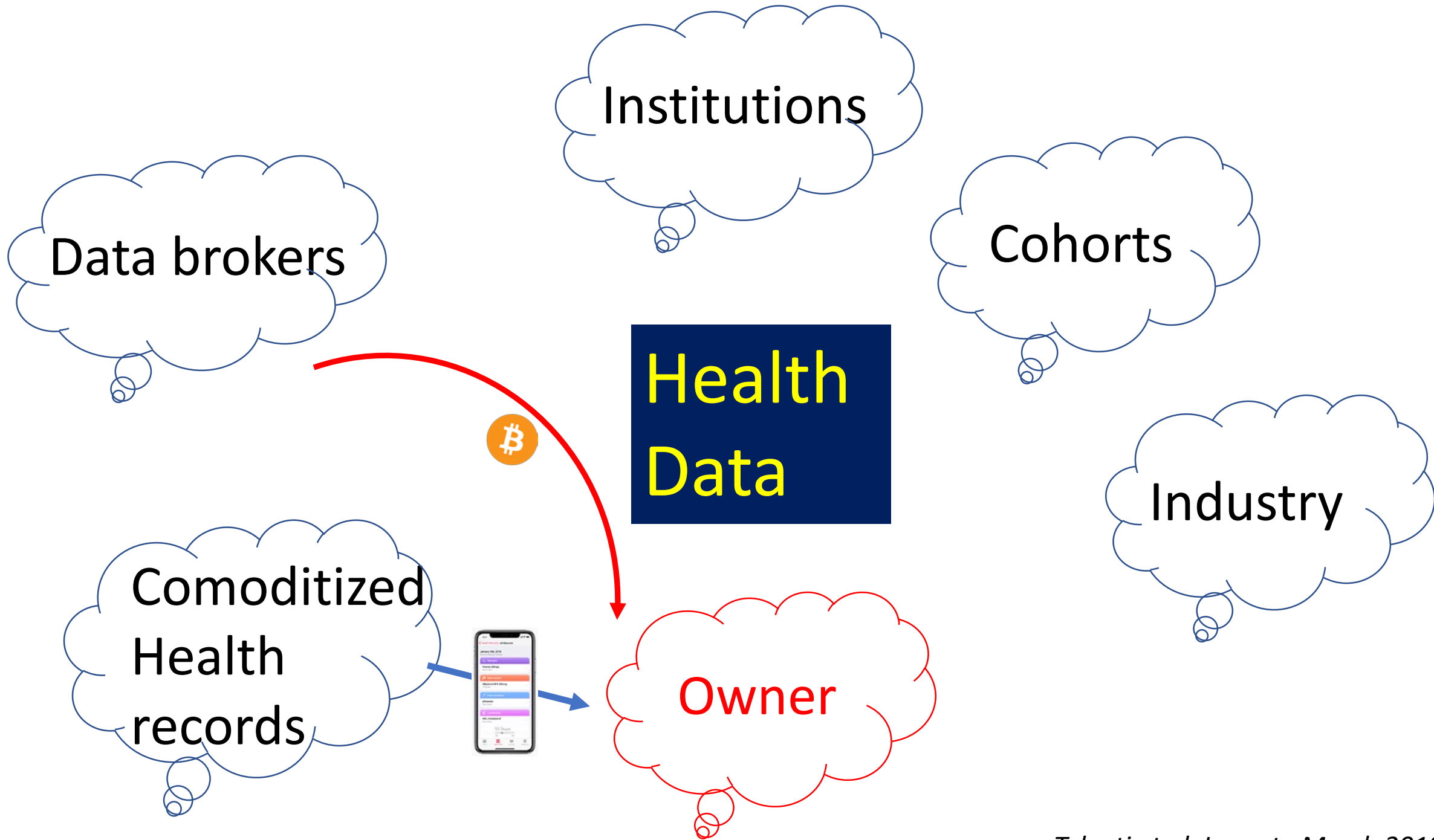
- There is a lot of health data being created
- The rise of alternative models in the data market
- Risks and solutions for data protection

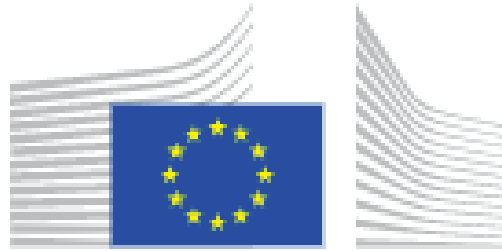
>>>Data ownership may lead to disruption in health care

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

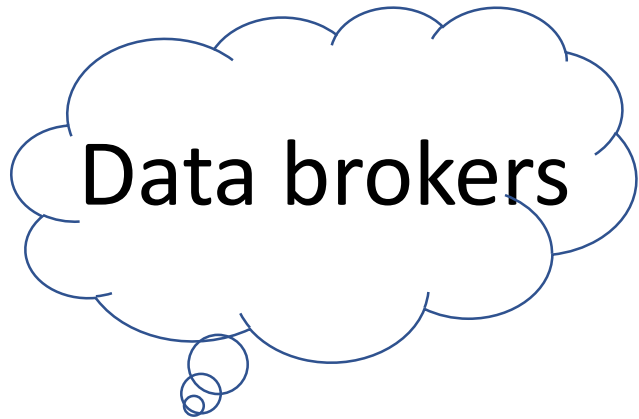




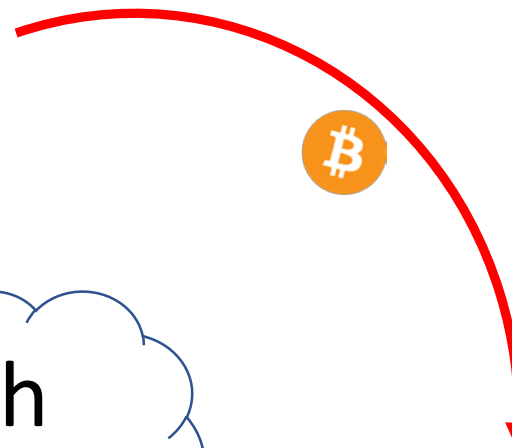
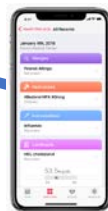
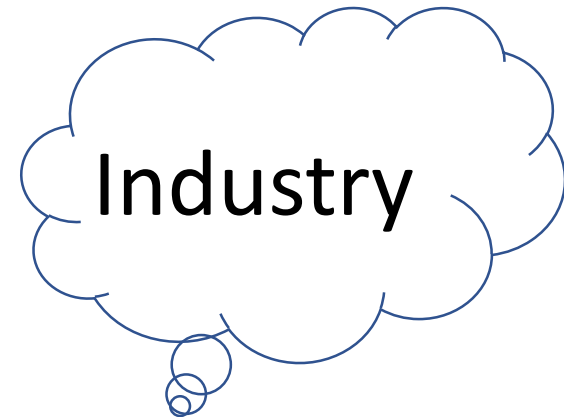
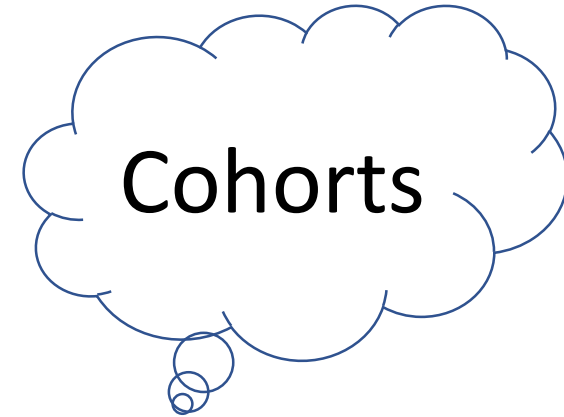
- Integration of genome-based knowledge and technologies into public health research, policy and practice (PHG)
- HNA (Health Needs Assessment), HTA (Health Technology Assessment), HIA (Health Impact Assessment) and PIA (Policy Impact Assessment)
- Knowledge base for evidence-based policy-making
- Interdisciplinary 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*





Lessons from other industries to drive a better healthcare supply chain

Wednesday, September 18th, 2019 | 12:00 - 1:00 pm CT

BECKER'S
Hospital Review

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Mayo Clinic taps Google for analytics, innovation, cloud computing

Andrea Park - 24 hours ago [Print](#) | [Email](#)



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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*

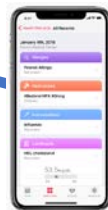
Institutions

Cohorts

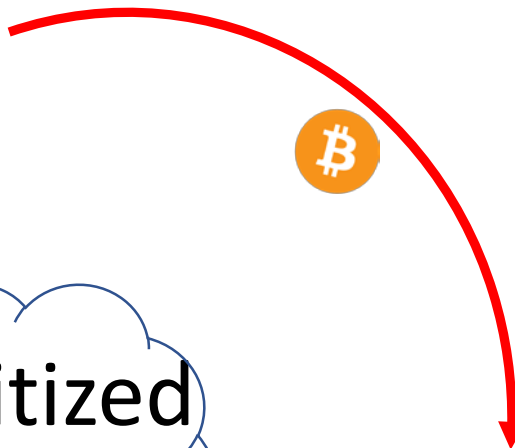
Industry

Health
Data

Comoditized
Health
records



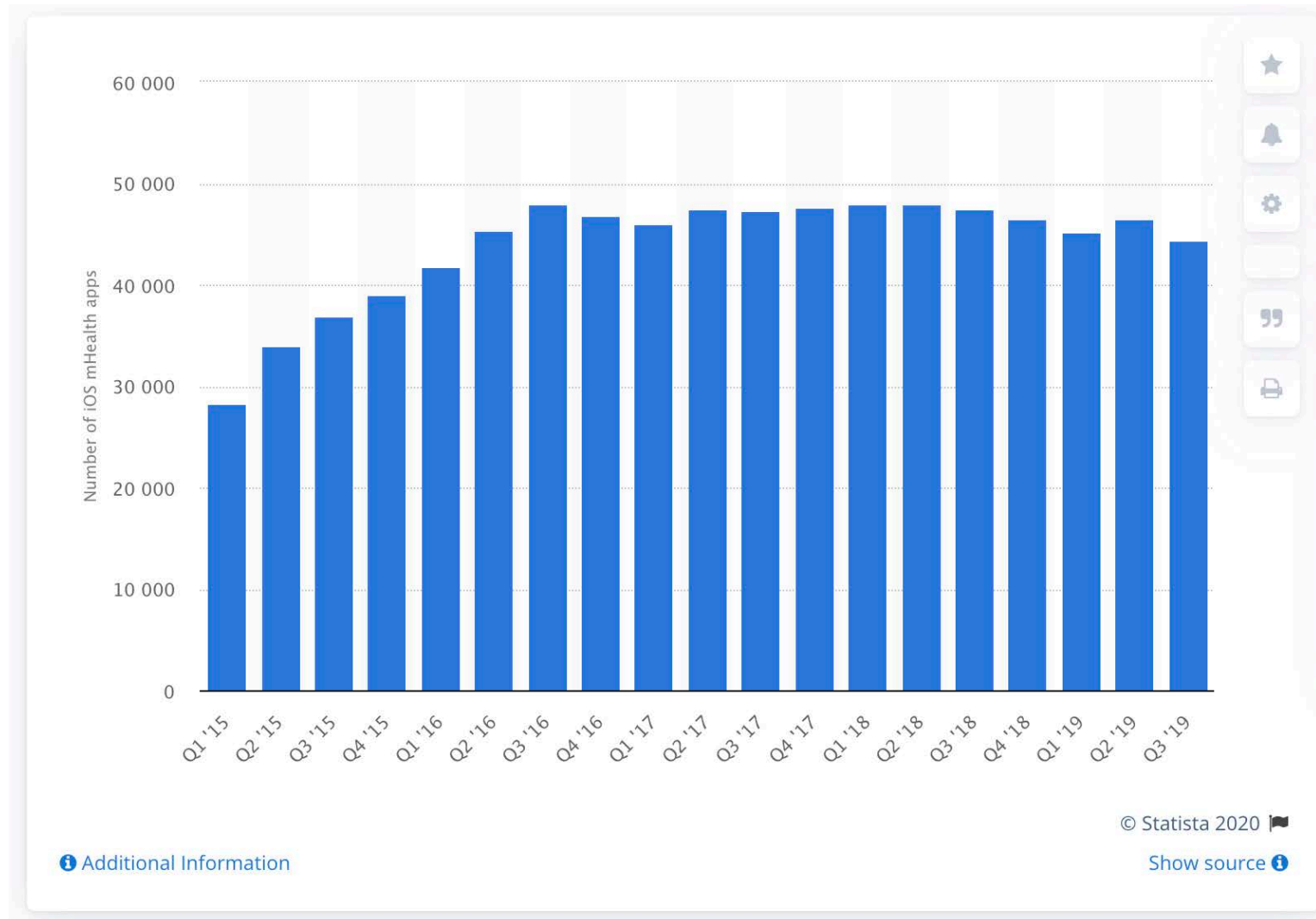
Owner



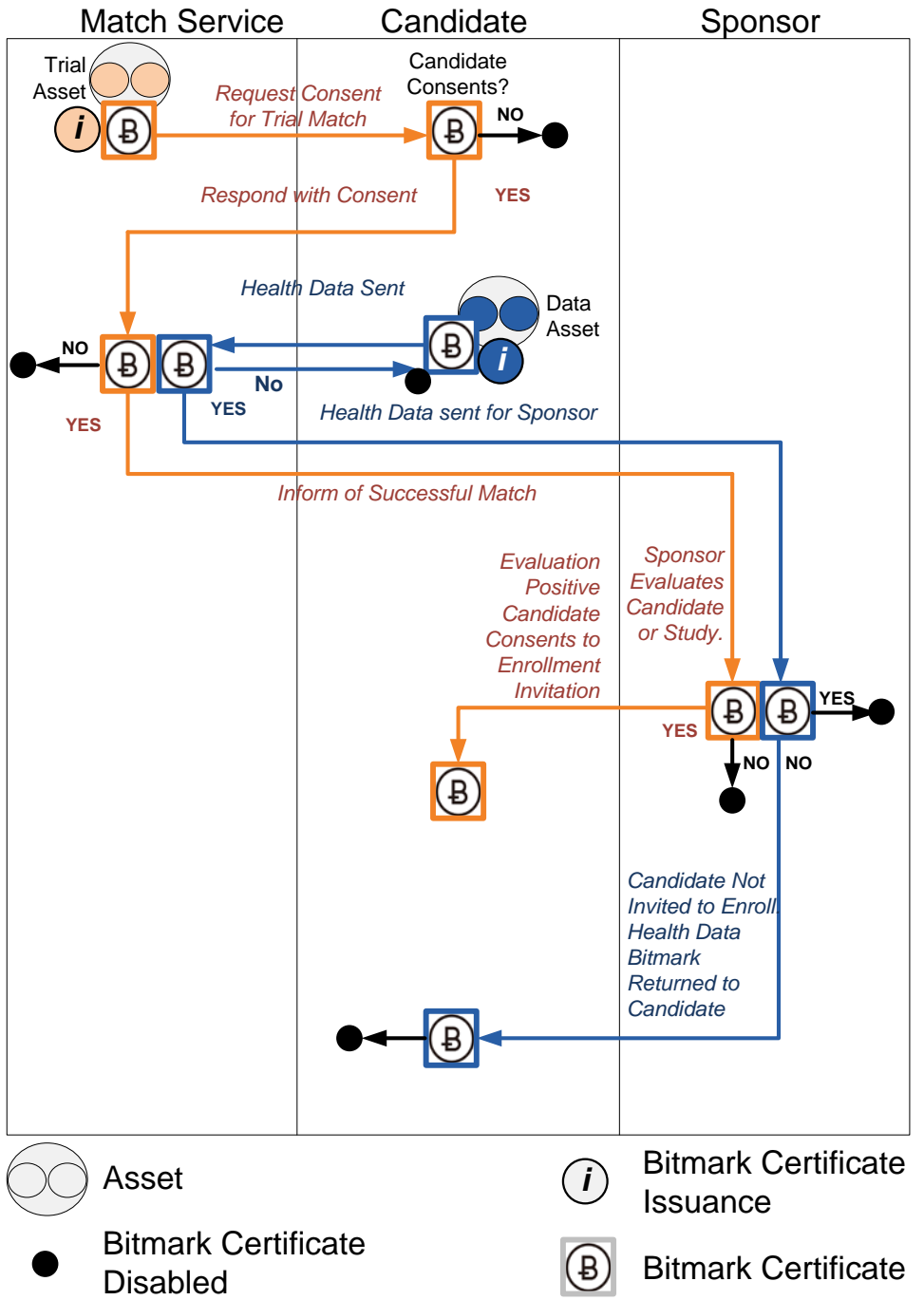
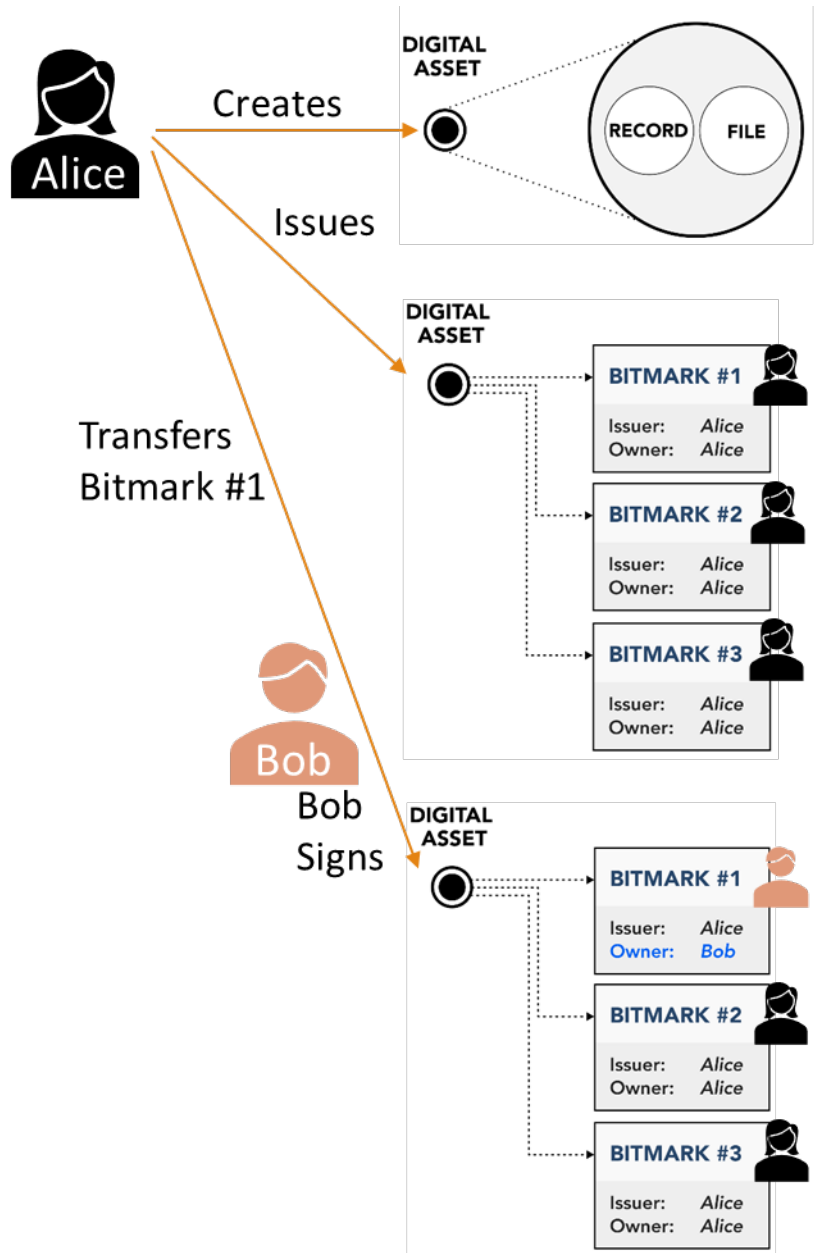
Medical history on the phone



Number of mHealth apps available in the Apple App Store from 1st quarter 2015 to 3rd quarter 2019

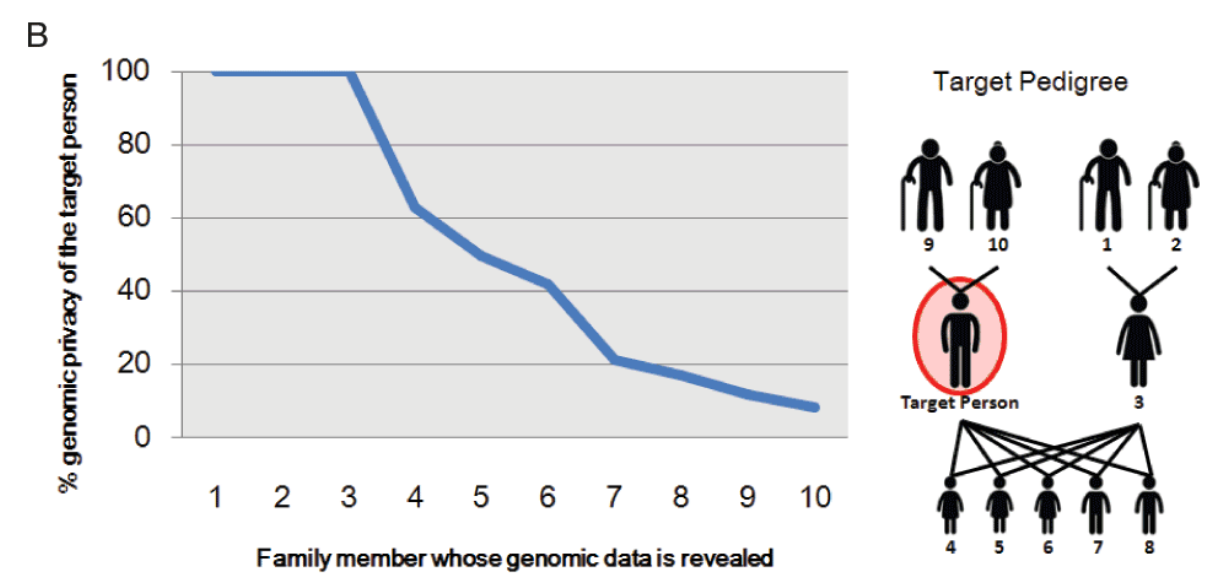
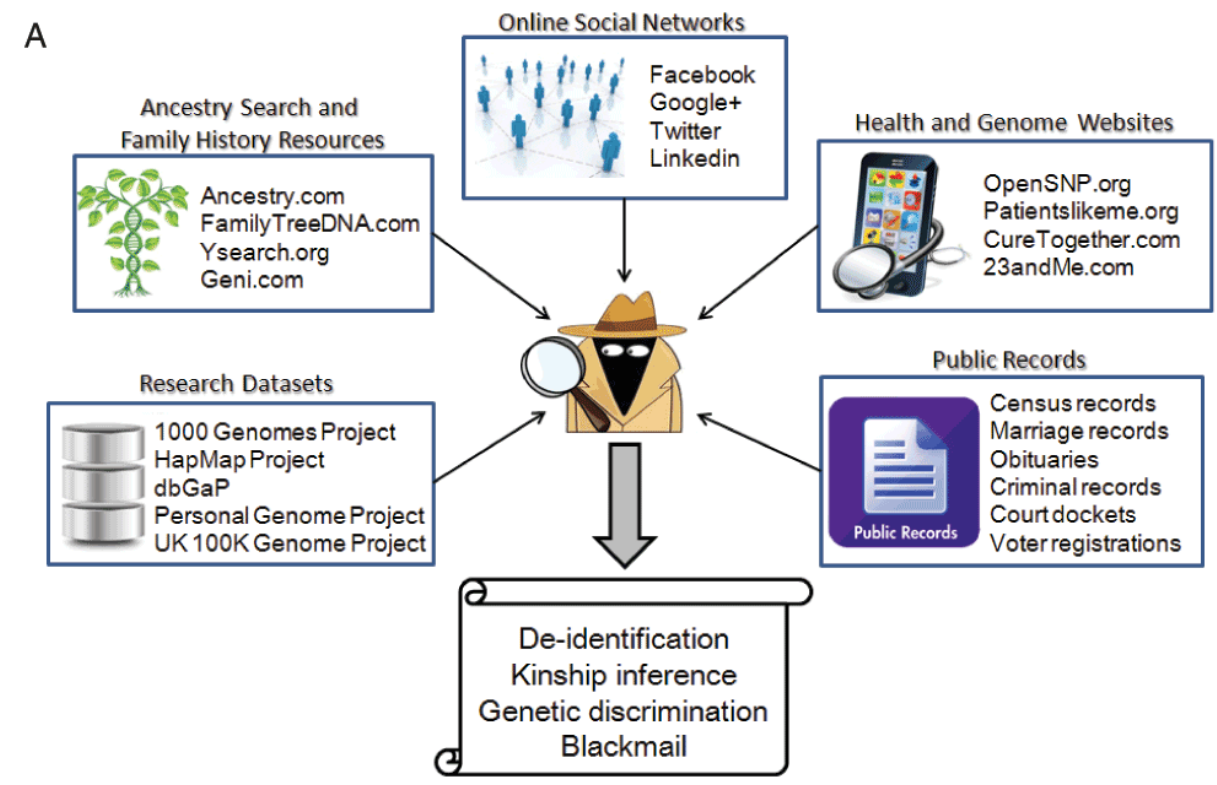


Blockchain contracts



Risks

Spread of genetic information via social media

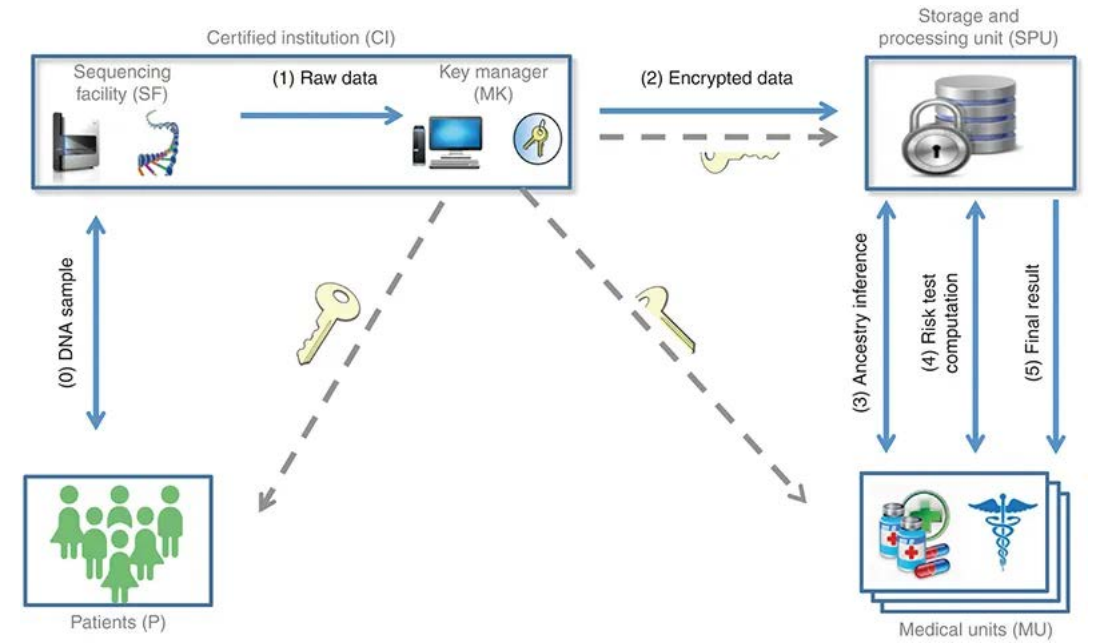


Solutions

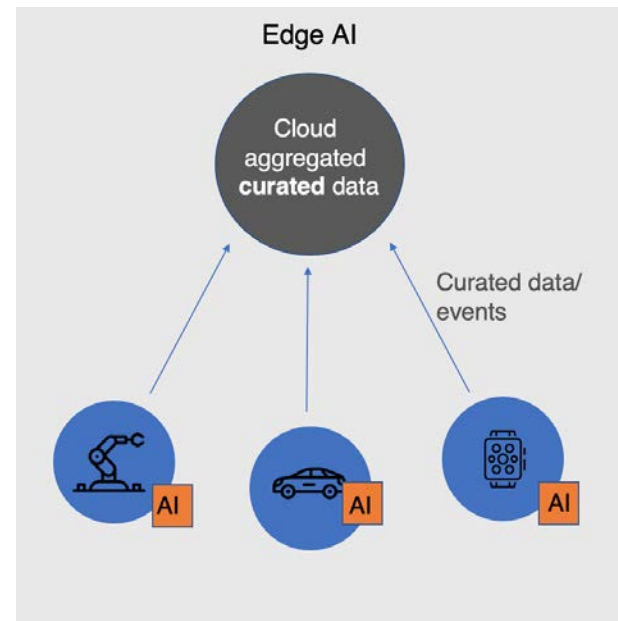
Sandbagging: Instead of the data going away for analysis, the algorithm comes to the institution.



Homomorphic encryption



[Genetics in Medicine](#) volume 18, pages 814–822 (2016)



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

Summary

- 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.