



Robinson+Cole

# Consumer Behaviors in Other Sectors

## National Academy of Medicine Leadership Consortium

# January 23, 2020

**Linn Foster Freedman, Esq.**

20256952

# Overview

---

- Introduction
- PHI versus Health Information (from the Consumer)
- Using Consumer Data for Patient Care + Population Health
- Recent Example of Consumer Incentives in the Law
- How are Consumer Collecting and Storing this Data?
- Health Apps
  - Examples
- DNA Testing Kits
  - 23andMe
  - Partnership with GSK
- How to Protect Consumer Privacy
- Conclusion and Questions



# Introduction

---

- **Imagine this.**

- Instead of giving away your personal data so that web giants can show you ads in your social media app, you cut out the middle person and allow advertisers and specific companies to pay you directly for your data or use your data to treat you.
- While this is still a novel idea, it starts to address consumer privacy by allowing more granular control over who gets our data.

- **So why can't the healthcare sector collect data and encourage patients/consumers to share their data under this existing model?**

# Protected Health Information v. Health Information

---

- **Protected Health Information** or “**PHI**” is a defined term under the federal Health Insurance Portability and Accountability Act of 1996 (“HIPAA”)
  - Limits uses and disclosures for Treatment, Payment and Healthcare Operations
  - Restrictive sharing of PHI without patient’s consent
  - Patient doesn’t control data dumping
- **Health Information** is the data related to a person’s medical history, including symptoms, diagnoses, procedures, and outcomes, family history, diet, lifestyle, etc. collected and **controlled by** the individual patient (**consumer**).

# Using Consumer Health Data for Patient Treatment + Population Health

---

- A patient's health information can be viewed individually, to see how a patient's health has changed or for monitoring;
- **BUT it can also be viewed as a part of a larger data set to understand how a population's health has changed, and how medical interventions can change health outcomes.**
- If patients (consumers) are given more control over their own data (and the use of their data) we can increase health outcomes individually and overall population health.

# Using Consumer Data for Individual + Population Health (cont'd)



- If we provide incentives for consumers to share the health information that they track and collect, it could lead to better health care results and outcomes.

# Recent Example of Consumer Incentives in the Law

---

## California Consumer Privacy Act (“CCPA”) Financial Incentives for Personal Information

- CCPA prohibits discrimination against consumers for exercising their privacy rights under this new law yet added a compromise exception for certain financial incentive programs
- CCPA permits businesses to **offer financial incentives or a different price** to consumers for sharing their personal information
- Codifying consumers’ willingness to share intimate and sensitive information for convenience or money

# Recent Example of Consumer Incentives in the Law (cont'd)

- **CCPA allows companies to provide financial incentives to consumers to entice them to allow the collection, sale or deletion of personal information**
- The exception allows businesses to offer a different price, level or quality of goods and services if the price or difference is directly related to the value provided by the consumer's data
- Consumer advocates debating whether consumers should be able to sell their data







BUSINESS | JOURNAL REPORTS: TECHNOLOGY

## Should Consumers Be Able to Sell Their Own Personal Data?

Two advocates square off over whether consumers will be helped or hurt by being able to own and sell their own data

Oct. 13, 2019 9:00 am ET

 PRINT  TEXT

21 

People around the world are confused and concerned about what companies do with the data they collect from their interactions with consumers.

A global survey conducted last fall by the research firm Ipsos gives a sense of the scale of people's worries and uncertainty. Roughly two-thirds of those surveyed said they knew little or nothing about how much data companies held about them or what companies did with that data. And only about a third of respondents on average said they had at least a

# How are Consumers Collecting and Storing Data?

- Mobile apps
- Wearable devices
- Ingestible devices
- Websites
- DNA testing kits



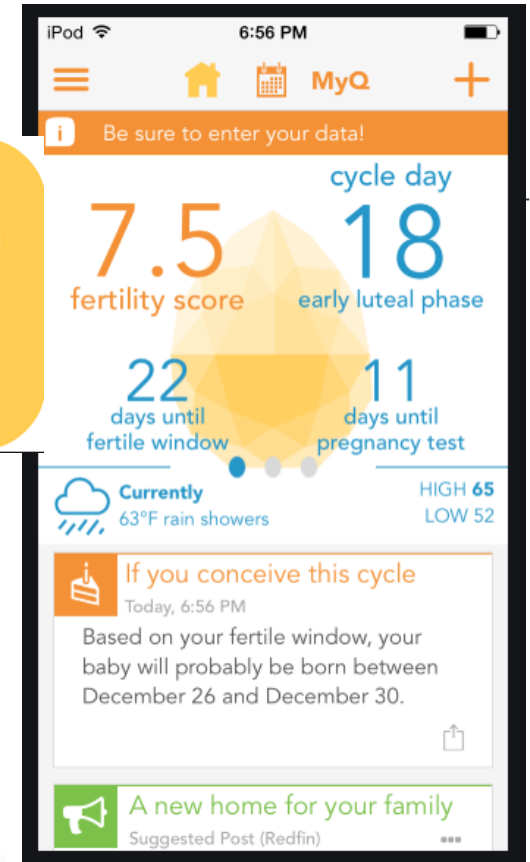
# Health Apps



**new** PatientSphere

Open Health Network Launches PatientSphere  
So Consumers Can Control and Monetize Their Medical Data

Platform uses Blockchain and smart contracts to enable HIPAA-compliant data sharing among various players in the healthcare ecosystem



# Health Apps (cont'd)

- **HealthWizz**

- Aggregates and organizes a user's medical data from hospitals, clinics and wearables, and then converts the data into a digital asset that can be shared privately and securely for reward points
- Cape Fear Valley Hospital asked discharged patients to enter some data daily into this app in exchange for HealthCoins (to exchange for rewards like Amazon gift cards)



# Health Apps (cont'd)

- **PatientSphere** (part of Open Health Network)
  - Offers HIPAA-compliant data-sharing capabilities to healthcare providers, medical researchers, pharmaceutical companies and health insurers
  - Patients pull data from EHRs, mobile health apps, wearable devices, chatbots, informatics programs (e.g. Apple HealthKit, Google Fit)
  - Uses blockchain for security



# Health Apps (cont'd)

- **Embleema**

- Sharing of medical records, compliant with HIPAA
- Allows consumers to put their data in the app, and then if they **CHOOSE**, authorize drug companies to access it in a de-identified manner and detect safety and efficacy signals early on and over a period of time
- Uses blockchain for security





# Health Apps (cont'd)

- **Ovia (Fertility)**

- Also has Ovia Pregnancy, Ovia Parenting
- Track your period, symptoms, moods, and more
- Receive accurate predictions for period and ovulation
- Explore articles, fertility facts, and health tips
- Read personalized summaries of your health and fertility
- Connect with an anonymous community of women
  - *What about connecting with your doctor???*



- **The Bump**

- Prepares every mom-to-be for each doctor visit
- Interactive 3D visualization of baby's growth

# Health Apps (cont'd)

- **Nebula**

- Private and secure way to learn about what your genes say about your traits and ancestry
- Customized reports on new variants, risk scores and research
- Earn rewards for answering surveys and contributing to research
- “Share data on your terms” is their tagline





# DNA Testing

As of last year, more than **26 million consumers** added their DNA to the leading genetic testing companies' databases voluntarily.

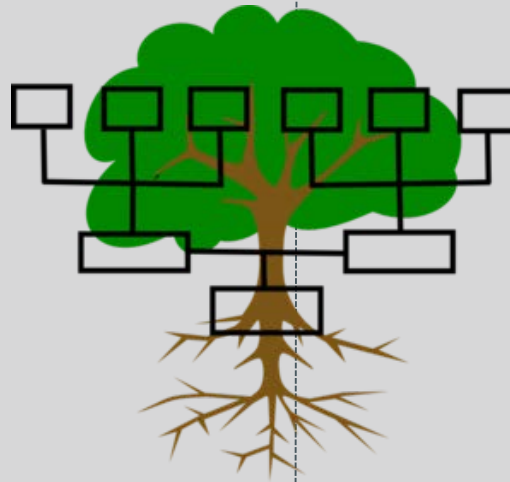
# DNA Testing (cont'd)

---

- Genetic testing companies are providing consumers with an unprecedented level of access to their personal genome.
  - Ancestral origins
  - How DNA influences your facial features, taste, smell and other interesting traits
  - Whether you are a carrier of certain inherited conditions
  - Health predispositions
  - Proactive role in health, wellness and lifestyle

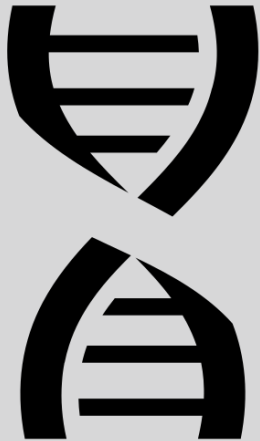
# Leading Genetic Testing Companies

- Veritas Genetic
- **Ancestry.com**
- **23andMe**



- **Helix**
- MyHeritage
- Family Tree DNA

# What kind of data are they collecting?



- Registration information
  - Name, email, address, user ID, password, payment information
- Self-reported familial and health information
  - Disease conditions, personal traits, ethnicity, family history, lifestyle information
- DNA (biological sample)
- Sensitive information
  - Health, racial/ethnic origin, sexual orientation, political affiliation



# Privacy Policy

- Uses
    - To provide services, for research (with consent); targeted online advertising
  - Choice with whom to share data
    - Doesn't share with public databases
    - Doesn't share with employer or insurer
    - Doesn't share with law enforcement unless required by law
  - Multi-Factor Authentication
  - Employee access controls
  - Encryption
- Ability to share with others via social media
  - If you do not consent for research purposes, your saliva sample and DNA are destroyed
    - \*National Institutes of Health Certificate of Confidentiality
  - Confidentiality contractual provisions with third parties
  - User Rights
    - Access, correction, deletion (unless already shared with third parties)

# The 23andMe Disclaimer

---

- There may be some consequences of using 23andMe Services that you haven't considered.
  - You may discover things about yourself and/or your family members that may be upsetting or cause anxiety and that you may not have the ability to control or change.
  - You may discover relatives who were previously unknown to you, or may learn that someone you thought you were related to is not your biological relative.
  - In the event of a data breach it is possible that your data could be associated with your identity, which could be used against your interests.

TRANSPARENCY AND CHOICE FOR THE  
CONSUMER

# 23andMe/GlaxoSmithKline Partnership

## **GSK and 23andMe sign agreement to leverage genetic insights for the development of novel medicines**

**Multi-year collaboration expected to identify novel drug targets, tackle new subsets of disease and enable rapid progression of clinical programmes**

GSK and 23andMe today unveiled an exclusive four-year collaboration that will focus on research and development of innovative new medicines and potential cures, using human genetics as the basis for discovery. The collaboration will combine 23andMe's large-scale genetic resources and advanced data science skills, with the scientific and medical knowledge and commercialisation expertise of GSK. The goal of the collaboration is to gather insights and discover novel drug targets driving disease progression and develop therapies for serious unmet medical needs based on those discoveries.

With over 5 million customers, 23andMe offers those with an interest in genetics the opportunity to learn more about their personal genetic profile. 23andMe customers can also choose to participate in research and contribute their information to a unique and dynamic database, which is now the world's largest genetic and phenotypic resource.

This type of data sharing could lead to a higher quality of data collection and more accurate analysis.

---

Digitization of health care information (from the CONSUMER), could also lead to improvement of healthcare quality and decline in chronic disease.





# How Do We Get Consumers to Share Their Health Information with Providers?



# How Do We Authenticate the Data?

---

- In December 2019, NCPDP and Experian Health announced that every person in the U.S. population, of an estimated 328 million Americans, have been assigned a unique Universal Patient Identifier, powered by Experian Health Universal Identity Manager (UIM) and NCPDP Standards<sup>TM</sup> (the “UPI”).
- The UPI is a vendor- and provider-neutral solution for accurately matching and managing patient identification across the healthcare ecosystem.
- Paves the way for profoundly reducing the risk of medical errors and improving patient safety.

# How Do We Authenticate the Data? (cont'd)

- The UPI is a number that is not known to the patient or provider. It is not intended to be a patient-facing number in an effort to prevent misuse of the identifier. The UPI does not collect or share any clinical claims or diagnostic information.
- Multi-factor Authentication
- Facial Recognition
- IP Addresses




# How to Protect Consumer Privacy?



- Using a “consent as a service” model: that is, extracting medical information from users who “consent for privacy” and “authorize for permitted use”
  - **CONSUMER CHOICE**
- MORE transparency upon enrollment in incentive programs and in privacy policies
- Use of blockchain technology for secure transfer and payment





There can be a **HAPPY MEDIUM** between selling and protecting data

# Conclusion

Patient-consumers can grant health care providers and organizations as well as research organizations access to their personal health information **AND get paid for it or obtain other benefit**

In return, certain entities can gain data specific to a particular patient **to better treat that patient** or get anonymized data that they can use for **population health**





**Linn Foster Freedman**  
**lfreedman@rc.com**

**Robinson + Cole**  
**One Financial Plaza**  
**Suite 1430**  
**Providence, RI 02903**  
**401-709-3353**

**Thank you**

**QUESTIONS?**

**[www.dataprivacyandsecurityinsider.com](http://www.dataprivacyandsecurityinsider.com)**