Disclosures

Blind-ish Trust
No involvement in investments since 1995

Academic Appointment @ MIT

Own $1.8M/yr business
70% of revenue from commercial, 30% from org + gov

Patents & personal health data are licensed under open source
Medicine is a noble profession.
Sir Thomas Browne, 1635

Healthcare is a noble business.
CIO, Boston-based Hospital, 2019
Yes, it is noble.

And there are plenty of blisters using that nobility ethos as cover, as a shield, to obscure their activities.
25% healthcare GDP

Juan Enriquez
1% of Global GDP
Sloan Kettering’s Cozy Deal With Start-UpIgnites a New Uproar

At Memorial Sloan Kettering Cancer Center in Manhattan, doctors and staff objected to a for-profit venture that could be lucrative for a few leading researchers and board members.

Gabriella Angotti-Jones/The New York Times

By Charles Ornstein and Katie Thomas

Sept. 20, 2018

This article was reported and written in a collaboration with ProPublica, the nonprofit investigative journalism organization.

An artificial intelligence start-up founded by three insiders at Memorial Sloan Kettering Cancer Center debuted with great fanfare in February, with $25 million in venture capital and the promise that it might one day transform how cancer is diagnosed.

The company, Paige AI, is one in a burgeoning field of start-ups that are applying artificial intelligence to health care, yet it has an advantage over many competitors: The company has an exclusive deal to use the cancer center’s vast archive of 25 million patient tissue slides, along with decades of work by its world-renowned pathologists.
Top Cancer Researcher Fails to Disclose Corporate Financial Ties in Major Research Journals

A senior official at Memorial Sloan Kettering Cancer Center has received millions of dollars in payments from companies that are involved in medical research. His omissions expose how weakly conflict-of-interest rules are enforced by journals.

by Charles Ornstein, ProPublica, and Katie Thomas, The New York Times, Sept. 8, 1 p.m. EDT

Jose Baselga
Chief Medical Officer
Sloan Kettering Cancer Center
An Assault on Ethics

Broke hospital Conflict of Interest rules:

Board/advisory roles with Roche + Bristol-Myers Squibb

Ownership stake in cancer therapy startups

Payments received from companies connected to cancer research in his articles (published by Cancer Discovery, of which he was one of the two editors in chief)

Public positive spin on two Roche-sponsored clinical trials (without COI recognition that for the past 4 years, he’s received $3+MM from Roche)

https://www.propublica.org/article/doctor-jose-baselga-cancer-researcher-corporate-financial-ties
The company, Paige.AI, is one in a burgeoning field of start-ups that are applying artificial intelligence to health care, yet it has an advantage over many competitors: The company has an exclusive deal to use the cancer center’s vast archive of 25 million patient tissue slides, along with decades of work by its world-renowned pathologists.

Memorial Sloan Kettering holds an equity stake in Paige.AI, as does a member of the cancer center’s executive board, the chairman of its pathology department and the head of one of its research laboratories. Three other board members are investors.

Patient data owned by hospital
 Paid for by the public
 100s of clinicians encoded/decoded/researched the data
 Making the rich, richer
Hospital pathologists have strongly objected to the Paige.AI deal, saying it is unfair that the founders received equity stakes in a company that relies on the pathologists' expertise and work amasssed over 60 years. They also questioned the use of patients' data — even if it is anonymous — without their knowledge in a profit-driven venture.

In addition, experts in nonprofit law and corporate governance have questioned whether Memorial Sloan Kettering, one of the nation's leading cancer centers, complied with federal and state law governing nonprofits when it set up the deal. The experts pointed out that charitable institutions like Memorial Sloan Kettering must show that they didn't provide assets to insiders for less than the fair market value.

Work by many, paid for by grants

Again, patient data owned by hospital

Aint no such thing as Anonymity

The Gold Rush in the land of non-profits

No competitive bidding before licensing the data to a single company, Paige.AI
“It just seems awfully coincidental that the individuals involved happen to be people in control and influence of that asset, and they ended up with an exclusive use of it,” said Marcus S. Owens, a Washington lawyer who ran the Internal Revenue Service division that oversees tax-exempt organizations. “It seems to create a cascading series of conflicts for the operation of Sloan Kettering.”

The decision to license images of the patients’ tissue slides to a for-profit company also highlights the broader debate over the use of personal medical data, ranging from genetic information to, in this case, images of a person’s cells, for research and commercial purposes.
What kind of design is this?
Letter from the CEO + COO

Subject: IMPORTANT MESSAGE FROM CRAIG THOMPSON AND KATHRYN MARTIN

Dear MSK Colleagues,

This morning’s print edition of The New York Times carries a front-page story regarding an analysis of voluntary disclosures made by Dr. Jose Baselga to journals and at professional meetings. The matter of disclosure is serious.

MSK has robust programs in place to ensure the quality, safety, and excellence of MSK’s patient care and research. These programs govern how our staff should work with outside organizations, including the pharmaceutical industry. They apply to all members of the MSK community.

We have asked Dr. Baselga to review his disclosures and work with the various medical societies and journal editors to correct the record of appropriate papers and presentations as the journals and societies see fit. He started that process and has already been in communication with several organizations.

The issues surrounding author disclosures are complex, as there are nebulous guidelines about when and how to make voluntary disclosures. We also believe in supporting academic freedom and the ability of individual researchers to engage in the scientific process, including publication of results. This extends to the judgment exercised by individual researchers and their responsibilities as authors with regard to disclosure.

MSK and our faculty need to do a better job. In addition, we need to work with journal publishers and professional societies to standardize the reporting process. We have had ongoing discussions with the American Society for Clinical Oncology about their model, as well as the value of a common standard for oncology disclosures in journals and presentations. We are supportive of ASCO’s efforts in this area and the leadership demonstrated by that organization. The issue of disclosure extends well beyond the world of oncology and MSK will also look to the efforts of other organizations, including the Association of American Medical Colleges.

Our work with industry partners is integral to MSK’s charitable mission of providing high-quality cancer care, leading research, and medical education with the goal of improving cancer treatment. Collaboration with industry leaders, from early stage startups to large corporations, is necessary to focus on bringing better treatments to patients.

MSK will continue to promote transparency and accountability. And we encourage industry collaboration, as it is a driving force that has led to the approval of novel, life-saving cancer treatments for countless patients across the globe.

“MSK has robust programs in place to ensure the quality, safety, and excellence of MSK’s patient care and research.”

“The issues surrounding author disclosures are complex, and there are nebulous guidelines about when and how to make voluntary disclosures. We also believe in academic freedom…”

Excuse by chaos.

Reporting guidelines = “complex” and “nebulous.”
Hospitals own the data
Patients have no ownership rights

IP, patents owned by executives
Funded by the public

Abuse of public funding for private gain
Corporate welfare

The rush for $$ over everything else
*Ethics as situationally optional*
Pharma-Funded Psychiatrists Behind Bogus Child ‘Bi-Polar’ Epidemic—Disciplined for Conflicts of Interest

The primary promoters—inventors, one might say—of diagnosing children with “bipolar” disorder, who for over a decade, aggressively promoted the bipolar diagnosis and use of antipsychotics in children, were disciplined by Harvard University and its affiliated Massachusetts General Hospital.

An investigation, prompted by Sen. Charles Grassley, was conducted by Harvard University-affiliated Massachusetts General Hospital. It concluded (earlier this month) that psychiatrist Joseph Biederman and two of his proteges, Thomas Spencer and Timothy Wilens—each of whom failed to disclose millions of dollars they had each received from the makers of antipsychotics, the drugs they promoted for the treatment of bipolar in children—had indeed violated the University’s and hospital’s conflict of interest reporting standards. The companies that paid them millions include: Eli Lilly, Johnson & Johnson, Pfizer, GlaxoSmithKline and Bristol-Myers Squibb.

Harvard Psychiatrists Disciplined for Conflicts of Interest


By Vera Sherav

The primary promoters—inventors, one might say—of diagnosing children with “bipolar” disorder, who for over a decade, aggressively promoted the bipolar diagnosis and use of antipsychotics in children, were disciplined by Harvard University and its affiliated Massachusetts General Hospital.

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We are complicit.

We, United Statesians, are sloughing data everywhere, without rights, and it feeds Kendall Square, Mountain View, and Moscow.
Health Data is any information about a person’s life that assists in making decisions about health and wellness.
2000-2020

Does “patient data ownership” turn “the age of healthcare surveillance” into a net positive?
Giving Patients Control of Their EHR Data

David Blumenthal, MD, MPP and David Squires, MA

The Commonwealth Fund, New York, NY, 10021 USA

DOI: 10.1007/s11606-006-0071-9
© Society of General Internal Medicine 2006

The question of whether patients should be able to control the information in their electronic health records (EHR) provokes strong opinions. Some argue that the information rightfully belongs to patients, and they should be able to decide what is recorded and who can access it. Some clinicians, however, argue that because they have a duty to provide their patients with the best possible care, doctors should have unrestricted or nearly unfettered access to any information needed to meet that obligation.

In our view, the patient’s right to control their own health information dominates. As Dr. Donald Berwick has eloquently professed, clinicians are guests in their patients’ lives. And as guests, they must respect the miles and wishes of their hosts, even when those preferences strike carers as misguided and even when they may compromise the patient’s well-being. Every day, patients choose (openly or covertly) not to follow clinicians’ recommendations—indeed, not to seek care at all. Carers have no right to overrule those wishes, even when they profoundly disagree. The idea of force-feeding patients medications or dragging them in handcuffs into the operating room would never occur to us. Assuming patients are mentally competent, we respect their right to control their bodies and their health care fates.

So it should be with their health data. It is perfectly reasonable for patients to be concerned about the deeply personal information contained in their records. Who has access to that information may have ramifications in the patient’s life, both inside and outside the health system, that clinicians cannot fathom. The person best positioned to make judgments about the use of their data—and the only person with the right to make that judgment—is the patient.

This view is reflected in the Fair Information Practice Principles adopted in 2008 by the Office of the National Coordinator for Health Information Technology, which underlie the federal government’s efforts to encourage privacy, transparency, and accountability for electronic health information. Among these is the principle of individual choice—that “individuals should be provided a reasonable opportunity and capability to make informed decisions about the collection, use, and disclosure of their individually identifiable health information.”

With rights, however, come responsibilities. When patients’ decisions affect the well-being of others, then the rules change. An individual who has been exposed to Ebola cannot restrict access to that information. A patient who is actively abusing substances should not be allowed to withhold that information from clinicians who may, as a result, unwittingly perpetuate illegal behavior—and endanger third parties who may be affected by the intoxication of the patient.

Furthermore, in controlling their health information, patients assume responsibility for the consequences of their choices. They cannot hold carers legally or professionally liable for negative outcomes that stem from lacking information that is purposefully missing or hidden. Patients must accept the attendant risks associated with their data decisions.

However, patients cannot competently assess those risks unless they are meaningfully informed of the consequences of restricting access to their electronic records. This poses a considerable challenge: most patients (and, indeed, most carers) currently have little understanding of how health information is shared and used. Kelly Cali et al., in this issue, describe how initially half of the patients participating in the Eskemazi Health study had little or no idea what was contained in their EHR, and none were fully informed about who had access to it.

Furthermore, knowing what is in one’s health record is insufficient to give patients a sense of why certain carers may need certain information. The ways in which carers use information are often non-linear and unpredictable. For example, knowledge of drug side effects and their interactions with other medications changes over time. A patient’s decision to withhold data about a sensitive medication—such as a psychotropic or HIV-related drug—may have later consequences that neither patients nor clinicians could have anticipated. Beyond this, when evaluating a patient, experienced clinicians often rely on an array of data, including information not obviously related to the current problem, to raise and evaluate hypotheses about diagnosis and treatment.

Communicating to patients the inherent risks and potential consequences of their decisions is a challenge, but has ample precedent in modern medicine: the informed consent process. Clinicians have not always been expected seek their patients’ permission when providing invasive care. Only in 1914 did the courts rule that a surgeon performing an operation without the patient’s consent commits an assault. The need for informed consent has since become ingrained in the medical
SECTION 1: MEETING FRAMING MATERIALS

- Agenda
- Participant list

SECTION 2: BACKGROUND MATERIALS

A vision of a health system where patients own health data


Defining patient data ownership


Ethical and financial implications of patient data ownership

“Patients should own their data.”

Elizabeth Nabel in 2017, President of Brigham Health and Seema Verma in 2018, Administrator of CMS
This ain’t property ownership.
Patient Data Ownership in Massachusetts

Patients co-own or fully own every health data point about themselves.

Health data generated about the patient by a provider is co-owned by both parties.

Health data generated by the patient is fully owned by the patient with a right to possess, share, sell, or destroy.
The Pathway to Patient Data Ownership and Better Health

Digital health data are rapidly expanding to include patient-reported outcomes, patient-generated health data, and social determinants of health. Measurements collected in clinical settings are being supplemented by data collected in daily life, such as data derived from wearable sensors and smartphone apps, and access to other data, such as genomic data, is rapidly increasing. One projection suggests that a billion individuals will have their whole genome sequenced in the next several years. These additional sources of data, whether patient-generated, genomic, or other, are critical for a comprehensive picture of an individual’s health. Enabling access to personal health data, clinical or patient generated, may benefit patients and health care professionals. Research is beginning to show that providing patients with their complete health data may help improve their health. For example, timely access to laboratory results can increase patient engagement. Access to physician notes after appointments appears to encourage individuals to improve their health and participate in decision making, with electronically engaged patients demonstrating more successful medication adherence, quality outcomes, and symptom management. Economic benefits may include the avoidance of duplication of diagnostic imaging or laboratory tests. Clinicians may also benefit from more informed patients. For example, they may score higher in quality performance programs because patients who are more informed may better adhere to treatment plans and hence may improve clinician performance scores. Despite growing evidence of such benefits, albeit with limited patient outcomes, and legislative and regulatory initiatives that facilitate electronic patient engagement, patients’ access to a complete, longitudinal digital health record remains rare. While such access may be possible for certain patients who receive care within a few select health systems, it remains elusive for many others, including patients who have changed physicians, lived in different places, have multiple chronic conditions, or who have had services provided outside of a clinical setting such as through a home health service.

Health care needs pressure to embrace interoperability, is poised for transformation. The potential for future system improvements is vast, but depends, in part, on increased patient participation. Health care must find a way to shift from “the doctor will see you now” to “the patient will see the doctor now.” Patients need engagement beyond passively receiving services, but this will be challenging until they can casually access and use their health data. For this to proceed, control of health data must be transferred to the patient or the patient’s authorized representative. More specifically, to obtain active patient engagement and system improvement, 3 components are necessary: (1) common data elements that enable the sharing and merging of health data from multiple sources; (2) a patient encounter data receipt, comprised of relevant health data from each health care encounter, automatically pushed to the patient’s complete digital health record; and (3) a contract between patients and third-party health data managers (eg, health care organizations and commercial entities) that enables individuals to control their longitudinal digital health record. Most of these components already exist in some form, requiring only minor adjustments to affect health system transformation.

Clinicians, patients, and health care systems need a way to efficiently receive, integrate, understand, compute, and use digital health data from other practitioners and health encounter locations. This requires the merging of what is often disparate data from multiple sources, and the most effective way to do this is to establish common data elements diagnostic of any particular vendor’s electronic health record (EHR) system. With widespread implementation of common data elements and value sets, semantic and clinical interoperability can be achieved, and health information can be merged, while maintaining data integrity. New initiatives, such as the Standard Health Record, that focus on standardizing data within health records instead of solely on exchange standards enable the development of one complete, digital health record per patient containing health data merged from all of a patient’s clinicians and related health data sources. For example, applying common data elements to platforms can enable patients to add patient-generated data into the record in addition to clinician-generated data. With its common, unifying template, the Standard Health Record can also support a host of secondary uses, such as patient-centered outcome research, precision medicine, and precision public health surveillance. This common digital health data language is also anticipated to reduce translation and comprehension errors.

Common data elements have legislative and regulatory support. For example, the Meaningful Use objective for 2014 focuses on standardizing data within health records to enable individuals to view, download, and transmit certain health information, including vital signs and laboratory test results. Section 4003 of the 21st Century Cures Act also requires the Department of Health and Human Services to evaluate the need for a “core set of common data elements and associated value sets” to enhance the exchange of structured health information.

3 components are necessary:

1. common data elements that enable the sharing and merging of health data from multiple sources;
2. a patient encounter data receipt, comprised of relevant health data from each health care encounter, automatically pushed to the patient’s complete digital health record; and
3. a contract between patients and third-party health data managers (eg, health care organizations and commercial entities) that enables individuals to control their longitudinal digital health record.

Corresponding Author: Katharine A. Miller, JD, MITRE Corp., 320 Burlington Industrial Parkway, Bedford, MA 01730 (kmikk@mitre.org).
Data Completeness

Complete SHR

- Patient identification: 16% of SHR
- Patient support: 4% of SHR
- Current health and care plan: 36% of SHR
- Health history: 10% of SHR
- Social/environmental factors: 7% of SHR
- Behavior: 8% of SHR
- Emergency: 15% of SHR

Medications
- 9 data elements (fields)
  - Dose change
    - Effective date
    - Dose before change
    - Dose after change
    - Reason for change
  - Medication information
    - Last review or update
    - Reviewed by
    - Medication adherence
    - Non-adherence reason
    - Non-adherence detail

The macro categories to the left are from the SHR v01 presentation. Categories found in the SHR v02 file were nested under related categories from SHR v01.
Data Completeness Continuum
Data Completeness Continuum

- Identity
- Support
- Preferences
- Health Status
- Social/Environment
- Behavior
- Heredity/Genetics

Empty record

Partial record

Complete record
a side note...
Drawing pictures helps comprehension.

...duh.

Yet, academics, scientists, execs++ need evidence (like this) to get graphic storytelling included as part of products.
the OPENHUMANS ECOSYSTEM

DATA + PROFILE
- genomics
- environment
- traits
- profile
- studies
- log
- quantified self

INTEROPERABLE DEVICES AND SERVICES

MEMBER
- TISSUE

MEMBER
- input DATA to create VIRTUAL HUMAN AVATARS of themselves

LAB
- samples from the BIOBANK are analyzed here

RESEARCHER
- research studies, like the POP! will members from OPENHUMANS into their activities

DATA SCIENTIST

CITIZEN SCIENTIST

COMMERCIAL COMPANIES

WEBSITE = AIR TRAFFIC CONTROL
EXERCISE IS MEDICINE

BRING THE EXAM ROOM TO ME

EXAMINE YOURSELF

DO WHAT MAKES YOU HAPPY

MANAGE DEATH
Patient Data Manager

Patient Health Receipt

Patient Data Use Agreement

Patient Health Record

You own your health data.

See it

Comment on it

Share it

Delete it

Transfer it

Remote consultation with Dr. Reel39A

Your 2 Feb. 19 visit summary

Encounter

Name: Jackie A24
DOB: 20 Jan. 72
BirthSex: Female
Address: 14 P Street, Boston, MA, 222

SourceOflnfor: Dr. Reel39A

EncounterClass: Outpatient
Diagnosis: Consult, Flu
Patient Data Manager

Collect your health data for sharing with anyone you want.

An open source project by MITRE

Let's Get Started

Sign In
IT'S YOUR DATA.
WE JUST MANAGE IT.

KNOW YOUR RIGHTS IN 3 MINUTES.
YOU OWN YOUR HEALTH DATA.
IT'S THAT SIMPLE.
YOUR DATA CAN COME FROM ANYWHERE... FROM YOU, A CLINIC, OR A DEVICE. WE PUT IT ALL IN THE SAME PLACE.
HAVING YOUR DATA IN THE SAME PLACE ALLOWS YOU TO SEE HOW IT ALL FITS TOGETHER (AND IT’S CONVENIENT).
MISTAKES HAPPEN. THIS IS WHY YOU CAN CORRECT AND COMMENT ON YOUR DATA.
YOU CAN SHARE YOUR DATA WITH ANYONE. WE ALWAYS NEED YOUR PERMISSION BEFORE SHARING YOUR DATA.
YOU CAN SHARE YOUR DATA WITH SCIENTISTS.
YOUR DATA WILL HELP US LEARN MORE ABOUT HUMANS AND DISCOVER CURES.
You can share your data automatically during an emergency. First responders would be able to see critical health information about you.
You can review who can see your data.
YOU CAN **STOP** SHARING YOUR DATA AT ANY TIME.
However, they will likely keep a copy of your data. But, they cannot get any new data when you stop sharing.
You can delete your data. We won't keep a copy.
You can transfer your data. We won't keep a copy.
The patient data manager is responsible for keeping your data safe. You can hold us accountable if there is a data breach from this application.
IT'S YOUR DATA.

YOU ARE IN CONTROL.
Signature

Type your full name to sign

☐ By checking this box, I understand and agree to the terms of the Patient Data Use Agreement and acknowledge that typing my name above represents my electronic signature.
Get control of your health data!

Create your account with the Patient Data Manager.

Email

Password
Now let’s connect your first source of health data.

On the next screen, you’ll see the health data already on your phone using HealthKit. Select the data you want to own.
Health

“MyHeart” would like to access and update your Health data in the categories below.

Turn All Categories On

Allow or disallow “MyHeart” to access all health data types listed here.

ALLOW “MYHEART” TO WRITE DATA:

- Height
- Weight

App Explanation:
To fully contribute to MyHeart Counts it is important for our researchers to have access to the data contained in Apple's HealthKit. Please grant MyHeart Counts access to this data.
Colon Cancer Care Plan

Prepare for treatment discussion
Here are some examples of the types of questions you may want to ask Dr. Rusk99 on 21.May, 10AM.

Health

Colon Cancer
Stage IB
Next Appt On Treatment
21.May
10:00AM

Health Receipt from Dr. Rusk99

You Time
Go for a 15m walk

Body Measurements

Conditions

This Week

Prepare for treatment discussion:
You may want to ask your doctor these questions before treatment begins.

What are my treatment choices? Which do you suggest for me? Will I have more than one kind of treatment?

What are the expected benefits of each kind of treatment?

What are the risks and possible side effects of each treatment? How can the side effects be managed?

What can I do to prepare for treatment?

How will treatment affect my normal activities? Am I likely to have urinary problems? What about bowel problems, such as diarrhea or rectal bleeding? Will treatment affect my sex life?

What will the treatment cost? Is this treatment covered by my insurance plan?
Authority and/or control over data explicitly stated in agreement

No data from the health record may be shared or used without the patient’s explicit permission

Can share data with other parties without limitation

Can compartmentalize data to share limited portions with identified parties

Can revoke a third party’s access to health record data and prohibit future sharing

Can annotate data in health record (while raw data maintained to maintain integrity)

Can delete all data

Can change PDMs

Can grant permission for emergency access to health record according to circumstances patient determines

Can donate or transfer data at death

Can get an accounting of disclosures/audit log at any time

Can get additional information about a disclosure upon request

Can hold Patient Data Manager (PDM) accountable for breach or malfeasance

Should have adequate notice of PDM termination of agreement and mechanism for transferring or saving health record

Can modify sharing and compartmentalization choices at any time
Additional considerations for patient data ownership:

Create a new category of IP law
...where property could be time-limited like copyright, allowing data to become publicly available after some time

Public ownership of anonymized data in aggregated databases

3rd party that aggregates and holds patient medical data, provides access to the data at the direction of patient
The last frontier for capitalism to sell: the human mind.
We demand patient data ownership rights.
data use agreement . org
And about those machines and models that process my data and poop out my care plan...
When you use a HC service, you don’t know how it works, why it works, who it works best for, and if the results are true.
I will share my medical knowledge for the benefit of the patient and the advancement of healthcare

Declaration of Geneva, 1948

Our black box algorithm risk-adjusts and care plans for half of US residents.

PBM, 2018
HEALTHCARE IS A HUMAN RIGHT
If healthcare is so noble,
if it’s key to our life on earth,
if we don’t have choice...

...we demand healthcare to be open.
The Internet is

... open source

... a human right.
Application
- Human-computer interaction layer, where apps can access the network services

Presentation
- Ensures that data is in a usable format, where data encryption can occur

Session
- Maintains connections, responsible for controlling ports + sessions

Transport
- Transmits data using transmission protocols (TCP, UDP)

Network
- Decides which physical path the data will take

Data
- Defines the format of data on the network

Physical
- Transmits raw bit stream over a physical medium

open source
Health Data Manager should be open source. Most healthIT is closed.

“We have anti-open source.”

Eric Topol
**National Digital Healthcare Experience**

Liis Hinsberg Shea
Former Estonian Health System Communication Director

"Digital healthcare is already a reality in 2018 in Estonia thanks to all the e-solutions we have implemented in the past twenty years," said Estonia’s Minister of Health and Labor Martins Silt at an interview last year.[2] Luckily enough, that statement was more newsworthy to people outside of Estonia than people living there and using e-government and e-health services on a daily basis. Estonians are very comfortable using e-services and sharing their data when necessary. Citizens are brought up with the philosophy that we own our data; however, it’s both the public and private sector’s job to use this data in the best way possible—to run our shared services smoothly and improve life in Estonia.

**Data travels on a digital highway**

Most public records in Estonia use the government’s open source data platform, the "K-speed or X-tee" data platform for both public and private data. The platform links individual servers, letting information live locally, but can be requested by different participants. The public sector uses X-tee for different registries like the Population Registry, Health Insurance Registry, Private Sector companies in energy, telecom and banking use the platform. Over 900 organizations use it daily.[3] The main user interface for citizens, enterprises and public officials is the State Portal "estatica".

Everyday services that people need are all online and necessary information or forms are pre-populated. When you vote, the e-voting platform already knows the necessary data. When you file taxes, the tax forms are filled out for you. You don’t have to insert any data more than once and there is no duplicate data.

**Estonia**

- **All residents**
  - $1.7B annual budget for all healthcare services
  - 0.9% Administrative overhead for Healthcare budget
  - 1.2MM or 94% of all Estonians and residents are covered by national Healthcare
  - $79 is the average cost per outpatient encounter

**United States**

- **Medicaid, Medicare**
  - $1.3T annual budget for Medicare + Medicaid healthcare services
  - 8% Administrative overhead for HHS/CMS budget
  - 108MM or 33% of all US citizens and residents are covered by national Healthcare
  - $121 is the average cost per outpatient encounter

- **Private**
  - $1.2T annual budget for private health insurance
  - 15% Administrative overhead for HHS/CMS budget
  - 156MM United States citizens and residents are covered by private Healthcare
  - $160 is the average cost per outpatient encounter

---

**In Estonia,**

95% of health data is digitized
99% of prescriptions are digital
100% of billing is done electronically
94% of citizens are covered by national healthcare

---

**Until 2016, it was named X-Road in English. Since 2016, however, X-Road is only used to refer to the technology developed together by Estonia and Iceland through Nordic Institute for Interoperability Solutions. The Estonian X-tee is now also called X-tee in English.**
Health Picture
Intervention Engine
Behavior Model
Treatment Agent
Diagnosis Generator
Patient Reported Outcome Pump
Review of Systems Sniffer
Determinants of Health Score
Patient Data Manager
Consent Routines
Patient Health Receipt
Patient Data Use Agreement
Data Completeness
Patient Health Record
Common Data Elements

Open Source Healthcare Services
“Epic EHR should be open source.”
Elizabeth Nabel, President of Brigham Health, 2017

“Open source is fundamental.
The fact that we don’t have open healthcare
reflects the deepness of our problem.”
Eric Topol, Scripps Institute, 2018
Healthcare and public health are a utility,
a human right, and
too important to be closed.
We live in a closed healthcare system. The algorithms that drive our care, to our clinical and life data, to hospital and treatment pricing, are governed by black-box services. By using these closed systems, we are actively designed out of the decision-making process, in favor of corporate “optimized care” for optimized returns (vs optimized health outcomes). Rect bias, to be accessible for rapid innovation and evolution, biases built into software, implemented with intent or accidentally, must be interrogated, examined, interrogated, companies and governments engage in healthcare for all.
Open Source Healthcare.org
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Sarah Kaiser,
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Parsuree Vatanasirisuk,
George Neyarapally,
Eric Topol,
Harry Sleeper

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