OPEN SOURCE HEALTHCARE

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Open source is something that anyone can change and share, because it's publicly available under a generous license. While it first began with computer code, open source now influences how projects and businesses work, and our lives benefit from this open sharing. Open source has grown into a way of participating with many others that asks for transparency, community-based collaboration, and meritocracy. The best ideas float to the top, and you earn trust by what you do and how you amplify the group.

Our internet is infused with open source ideas and services — from how cell phones communicate, to how e-mail is directed from one person to the next, to Linux. All of these technologies working together are the operating system of the internet.

Here in the US, healthcare is sometimes amazing, often lifesaving, always expensive, and mostly closed. It's tribal at its core — each hospital, each doc, each healthcare system invents its own way — to the detriment of our collective health.

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WE MUST SET HEALTHCARE FREE

We have open standards for finance

   because we value our money more than our health.

We have open standards for transportation

   because getting to your destination is a necessity.

We need open standards for healthcare

   because our lives depend on it.

We Demand Open Healthcare

to empower interoperability
Without open standards for health information, hundreds of different healthcare IT systems are currently unable to communicate with each other. This insular approach wastes up to $77.8 billion per year[25] in the United States alone, in addition to causing medical errors and stifling research.

to establish open standards of data
Development of non-proprietary healthcare standards will create an incentive for the providers of commercial healthcare IT products to adopt models of compatible data exchange and information systems; adopting open standards will open a path for them to stay competitive.[25]

to allow greater provider benefits
Using open standards to improve health information networks and electronic medical record systems will allow patient data to become more portable between healthcare providers than it is today, ensuring more accurate and efficient care for patients.

At the same time, having open source software options will free healthcare providers from being locked in with one vendor, and offer the added benefit of allowing them to customize the software to their specific clinical workflows and needs.[25]

to improve patient outcomes
With open source healthcare IT solutions, regions with limited resources that cannot afford expensive proprietary solutions will still have options for quality software to help them deliver quality care.[26] Most importantly, the open source model is consistent with the healthcare philosophy of sharing best practices and innovations in care delivery[25] to improve health — with benefits for individual patients, as well as the entire population.

Eric Topol, MD, is a classically trained clinician who fights for the patient and their rights as the atomic unit of healthcare, made crystal clear with his book "The Patient Will See You Now."

His Precision Medicine Initiative, funded by NIH, is out to make hyper-personalized medical care for all of us, all under the umbrella of open science, open data, open outcomes for all humans. Here are 5 key takeaways from our chat.

Eric Topol
Q&A

A National Standard

Data should not be put into a siloed environment in proprietary software systems. Let's go back to when the US put forty billion dollars towards health information technology, when they never had the teeth to tell companies, whether it be Epic or Cerner or Allscripts and all the others, that we all need common data requirements and standards that are completely open and transparent, that lead to a more seamless data source. Why didn't we do that? What is the problem in this country, where we don't force all companies that are active in Health IT to have these standards. Only in recent times have we seen a bit of a push towards that, but it's taking seemingly forever to get there.

We want each individual's data from prenatal all the way throughout their life. All these things need to be accessible so that any healthcare clinician, with the patient, will have access to all this data instantaneously. Your life data and its easy availability for the care team is what we should aspire to and eventually achieve.

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Put the Patient in the Driver's Seat

Everyone's medical record is full of errors. Wrong diagnoses, wrong medications. It's never been edited. The patient knows best about what actual medicines they're taking or not taking, or whether there're erroneous diagnoses. Again, the input of the human being, the driver of the care team, is not taken into account.

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Follow the Leader

We can take lessons from Estonia, where each individual citizen owns their data. If each person owned their data, many would want to share it with their clinicians. They would be very interested in having that data be used for research, that would help people with like conditions. Or patients will just help altruistically.

The Estonian model is being adopted in many other countries. Here in the US, we have this erratic, proprietary, closed model. Data ownership is fundamental because more and more of that data is being generated by the individual, with sensors, with phones, with genomic data.

20 million people have consumer genomic data that they have purchased themselves. And yet, that's not going to be assimilated into an electronic health record. Between the continued rush to genomics and sensors, there will be more and more lab testing.

The inflection point in data collection is here, where the doctor-maintained, aging electronic record, what used to be the paper record, is now only a small piece of your health picture.

Consumer phone cameras will perform retinal and skin exams. This is a fundamental shift from the hallowed electronic record to all these other sources of data about the individual that are equally as important, with even larger data sets.

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AmazonCare

Amazon is getting much more serious about entering healthcare because they already have the customer interface. They just purchased Pill Pack to deliver prescriptions to all 50 states. They have 70% of the country on Prime for rapid delivery. Those subscribers are trying to get their money's worth out of their annual fee.

Amazon, along with Berkshire Hathaway and JP Morgan, are set up and poised to make a difference. Amazon is a consumer-friendly platform, has very deep knowledge in the use of AI, with one of the early precedents of using AI for what merchandise any given individual might want or need. With AI taking center stage on your growing Amazon data, the triad of companies will have access to huge health data … and it's just getting bigger.

There are unlimited opportunities. Every individual should own their data, but that's probably not where Atul is going. They're trying to reduce costs and improve outcomes. Specifically, getting rid of the middle people like pharmacy benefit managers, that are taking money out of the system, without providing any improvement in efficiency.

It'll be interesting to see how Atul Gawande and the crew advances healthcare. You can't make it any worse.

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A Call for Open Source

I'm a big advocate for open everything, open to the 10th power. I think this is one of the major healthcare system deficiencies. We have to own our data. All of our data. It's hard to access, and even harder to pull the data out from proprietary electronic health records in a usable form. We have anti-open source.

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Open Source is ...

A Credo
Open source is a philosophy on how to make and use products. Employing extensive peer review and open evolution of community contributions results in higher-quality and more reliable software.[1] This transparency benefits private organizations as well as the greater public.[2]

A Collaboration
Several licenses are available to govern the terms of how open source collaboration functions. Being able to customize the level to which product source code, data, or processes are redistributable or modifiable means that the benefits from creating and using open source are available to an extremely wide range of businesses.[2]

A Form of Citizenship
Open collaboration extends beyond software into communities that share ideas and generate content, both digital and physical.[2] These communities amplify the reputations of their contributors, and create a reservoir of ideas that power open source products.

Hiding in Plain Sight: A Look at Everyday Open Source

Did you know that over 2 billion people use open source everyday?[3]
A 2011 analysis revealed that over 75% of the top 10,000 websites ranked by volume of visits ran on open source servers.[4] A later 2016 survey of over 1,300 IT executives revealed that 78% of the respondent companies ran all or part of their operations on open source software – that is nearly double the proportion reported in the 2010 edition of the same survey.[5] While open source is best known in software, its reach extends far beyond, to hardware, healthcare, research, content generation, government, and standards.

Android
Built on top of Linux, Android is a fully-featured operating system commonly used in mobile devices. The Android source code is fully open, allowing anyone in the world to learn from and build upon the codebase.

`www.android.com` ↗

Arduino
Used by hundreds of thousands internationally, Arduino is an open source hardware and software platform for exploring, prototyping, and building interesting and useful technology projects. Arduino's integrated development environment (IDE) is open source and the original design files for Arduino hardware are also available under an open source license.

`www.arduino.cc` ↗

Center for Open Science
The Center for Open Science supports the Open Source Framework (OSF), a set of standards promoting openness and transparency of scholarly research, funding of research, and access to research output. The OSF seeks to foster this open exchange of ideas for timely and effective solutions for disease, poverty, social injustice, and the consequences of climate change.

`www.cos.io` ↗

The International Organization for Standardization (ISO)
ISO develops and publishes standards specifying the behavior, functionality, and usage of products, services, and systems across nearly all industries, including technology, food safety, agriculture, and healthcare. ISO standards are developed through a consensus system drawing on the expertise of its 161 national standards body members.

`www.iso.org` ↗

Linux
Called the "most successful open source project in history," Linux is the world's most influential operating system. Linux is used by over 95% of the top 1 million websites, over 80% of smartphones, almost all of the top 500 fastest supercomputers, and most global stock exchanges.

`www.linuxfoundation.org/projects/linux` ↗

MIT OpenCourseWare (OCW)
This website from the Massachusetts Institute of Technology allows free access to nearly all of the university's course materials. MIT OpenCourseWare (OCW) holds materials from over 2,400 courses and has received over 300 million visitors since its creation.

`ocw.mit.edu` ↗

MySQL
MySQL is the world's most popular open source database used by many well-known businesses including Google, Facebook, Netflix, Spotify, Verizon, NASA, and the US Navy.

www.mysql.com ↗

Open Government
The US federal government's open data site hosts nearly a quarter million datasets covering nearly all aspects of the federal government's activities, including health, demographics, and the economy. Both the data and the code powering this data portal are freely available to access and examine.

www.data.gov/open-gov ↗

Open Government Partnership (OGP)
OGP is an international organization comprised of over 70 national and 15 subnational governments who have made commitments to harness new technologies to improve transparency of governance to citizens and reduce corruption. Since its inception in 2011, the OGP member countries have made over 2,500 commitments, with OGP ensuring accountability via its Independent Report Mechanism.

www.opengovpartnership.org ↗

OpenEMR
An open source electronic health record system that targets small to medium-size outpatient providers, OpenEMR is certified by the Office of the National Coordinator for Health Information Technology (ONC) to meet the 2014 edition of Meaningful Use guidelines in the US. OpenEMR enjoys broad adoption globally at over 15,000 healthcare facilities with over 45,000 practitioners serving over 90 million patients.

www.open-emr.org ↗

Public Library of Sciences (PLOS)
PLOS publishes influential scientific journals focusing on the life sciences: medicine, biology, genetics, computational biology, and diseases. To support its mission to equitably advance scientific knowledge, all PLOS content is freely available for the public to distribute and reuse.

www.plos.org ↗

Project Gutenberg
A volunteer-driven organization digitizing public domain books for public consumption at no cost, Project Gutenberg currently has over 56,000 e-books. Its collection is slated to grow with the expiration of the Copyright Term Extension Act of 1998, which granted a 20-year extension on copyright exclusivity.

www.gutenberg.org ↗

Wikipedia
One of the largest, collaboratively edited knowledge bases in the world, Wikipedia is overseen by the Wikimedia Foundation, which also operates an open source dictionary, textbook repository, news source, and image library as part of an overall mission to provide free and accessible educational materials for all.

www.wikipedia.org ↗

World Wide Web Consortium (W3C)
W3C develops protocols and guidelines for the web, including such fundamental concepts as URLs (colloquially known as "links"), HTML (the markup language used to specify the content of all human-facing websites), and HTTP (the transport protocol used to transfer data including web pages) across the web.

www.w3.org ↗

HOW THE TECH GIANTS ARE USING OPEN SOURCE

Amazon
Electronic commerce and cloud computing giant Amazon has deep roots in open source through support of well-known open source projects like Linux, Chromium, Xen, and Apache MXNet,[15] and through **open libraries for its services such as Alexa** and Elastic Container Service (ECS).

Apple
CareKit is Apple's open source framework for developing apps. Coupled with ResearchKit (also open source) and Healthkit (which ingests FHIR), it is an early green light for getting patient records synced in a single "view."

Facebook
A global social network with over 2 billion monthly active users,[13] Facebook has open sourced key parts of its internal tools for Android, iOS, web, backend, and hardware.[14] Its open source offerings include the prominent web and native application framework ReactJS and the graph database query language GraphQL.

Google
Many of technology conglomerate Google's products have open source underpinnings, including the Android mobile operating system and the Blink rendering engine powering its Chrome web browser.[17] Recently, Google open sourced Abseil, a collection of tools that **underpin almost all of Google services.**

IBM
IBM is a large multinational technology company that has **released over 50 open source products**, while contributing to over 150 other open source projects.[10, 11]

Netflix
Internet entertainment company Netflix leverages and contributes to open source to **scale and improve reliability of its streaming services,** from deployment workflows to backend technologies to frontend user interface tools.[16]

Red Hat
A multinational technology company, Red Hat, provides open source enterprise software solutions. Through a business model of subscription-based customer support and training, the company has hit a revenue of $2.4 billion in 2016.[12]

OPEN SOURCE IS CRITICAL FOR DIGITAL HEALTH

The success of open source and the current internet infrastructure has permeated into the futurist and executive visions of health as "the Uberization of Healthcare."

Our smartphones occupy 90% of US residents' pockets, infect our wetware, and plaster the healthcare venture world. From the corporate mountaintops to our own start-ups, we crave the immediacy of on-demand service (instant gratification, right now!), which requires the availability of on-demand labor, standard technologies and data schemas, and world-enabled protocols and services.

So what are we waiting for?

Those open standards, protocols, and services exist. They're available on a global scale. Web and mobile services were developed on, evolved on, and live on publicly-funded, standardized technology and infrastructures.
Think TCP/IP.
Think HTTPS.
Think GPS.
And keep in mind that airwaves and bandwidth are actually owned by citizens!

Billions of public dollars were spent on the Human Genome Project — yet we still don't have a common way to describe a human and our biology in code in a standard machine and human-readable way, which would be one of the most fundamental aspects of digital healthcare. While the results have been available in the GenBank Database (maintained by the National Center for Biotechnology Information) and will foster dramatic progress, ranging from molecular medicine to a better understanding of anthropology, they also encouraged thousands of attempts to privatize, and close off that knowledge, by trying to commercialize and patent parts of that human genome.

Not invented here

Healthcare companies make money on FUD: Fear, Uncertainty, and Doubt. They actively rally against standardization, from individual doctors thinking their own way is best (as opposed to drawing on collective data across medical practices), to hospitals and other healthcare organizations preferring to devote their resources to developing their own research and treatment regimens. They are trusting their own ways more than already existing, proven solutions from other providers, solely because they were "Not Invented Here."

On a national level, the push by the Obama administration to move the healthcare industry towards Electronic Health Records has most clinics and hospitals using a proprietary EHR. The current web culture, dominated by FAANG (Facebook-Amazon-Apple-Netflix-Google), shows little promise to return to its open source roots, but rather seems to be thriving on closed services.

Healthcare providers, including hospitals, clinics and clinician organizations, own our data and keep business by not standardizing that information, making data ingest from another organization painful. Even hospitals with the same EHR vendor, such as Epic, often have trouble reading data from installation to installation, which leaves third-party services, open or closed, out of the loop.

BILLION DOLLAR PAYWALLS

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After the passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act in 2009, which incentivized Electronic Health Record (EHR) adoption in the United States, a 2016 American Hospital Association survey found that 75% of its member hospitals had at least some basic EHR in place, up nearly five times from 2010 levels.[45] However, EHR systems in the US remain overwhelmingly proprietary, split up into carefully-guarded billion-dollar fiefdoms separated by paywalls.

As of 2016, two-thirds of the 8.6 billion dollar EHR market in the US were held by three major vendors: Epic at 25.8%, Cerner at 24.6%, and Meditech at 16.6%.[46] As of December 2017, examination of the 93 vendors with products currently certified by the Office of the National Coordinator for Health Information Technology (ONC) to meet 2015 Meaningful Use guidelines set forth by the Centers for Medicare and Medicaid Services (CMS) found only three vendors releasing open source products[32, 50, 51] and only two others who are active open source contributors.[47, 52]

Of the three open source products, two are based on Vista developed by the US Department of Veterans Affairs[32, 51] and the remaining is a former proprietary product that recently became open sourced.[50] Vista has not been a shining example of open source, considering its lack of external commits. It's dying now that Cerner won the government contract for replacing the aging Vista. The time is ripe for a national open source EHR to emerge.

The Patient is the Payer is the Consumer is the Citizen

Jane Sarasohn-Kahn

The advent of $4 generic drugs and growing tiers between prescription drug co-payments was my lightbulb moment, about twelve years ago, which got me thinking about the patient-as-consumer.

Back in 2006, Walmart disrupted the pharmaceutical world by introducing patients to generic drugs at a low price: $4 for a monthly supply.

Today, we take low-cost generics for granted, but they were a sentinel event that began the morphing of the American patient into a health care consumer. With Walmart's first move into the $4 generics world, patients began to shop around for generic deals on Rx drugs, and soon, other pharmacies adopted the $4 Rx plan as a kind of loss-leader to get consumers to shop in their stores, whether freestanding retail pharmacies or groceries with on-site pharmacists.

Since then, that consumer has taken on more financial and clinical responsibility through more people enrolling in high-deductible health plans, and through shopping on health insurance marketplaces, public and private alike.

At the same time, those patient-consumers have morphed into homo informaticus, that multi-platform, multi-channel human that is information-seeking on many channels. It's mainstream to "page Dr. Google" with symptoms and to research unpronounceable names of new medicines — their side effects and prices as well as their benefits.

That's the demand side: where patients-as-consumers have gotten more serious about getting smart and engaged with their healthcare: especially about cost, and eventually about access to personal medical records.

How people use their mobile phones and platforms for their daily lives — managing money, booking travel, finding restaurant tables, sharing rides, and ordering shoes and books and laundry detergent and pet food — that's the mainstream consumer, and she wants her life-flow for healthcare to be as streamlined and user-enchanting as the digital tools she uses with other industries she patronizes.

So we now must deal with the patient-as-payer.

Central to her ability to be that patient/consumer/payer is data liquidity, and data well-designed: with privacy, security, understandability, and accessibility baked in.

An old saw goes, "he who pays the piper calls the tune." Today, our personal workflows in healthcare don't feel at all like an Amazon Primed experience, where we are the payer and Amazon, increasingly, the e-commerce piper. The tune, we expect, is an elegantly designed smartphone app, financial services portal, or travel scheduler. Or, at a minimum, no surprise medical bills, the correct personal data in our EHR, and on-line bill payment, among a long list of demands we new healthcare consumer-payers deserve and, increasingly, demand.

Jane Sarasohn–Kahn is a health economist and advisor supporting organizations at the intersection of health, technology and people. Jane founded THINK–Health and the Health Populi blog after working for ten years with health care consultancies in the U.S. and Europe. Her clients are all stakeholders in health: technology, bio/life sciences, providers, plans, retail, financial services, food and consumer goods. Jane is a frequent speaker and also contributes to the Huffington Post.

In the U.S., health citizens should know that the nation ranks far down the quality roster of health system excellence. Americans spend more and get less.

Greater personal and patient health engagement can help drive better outcomes and bend our personal and public healthcare cost curves. Our access to "our" data helps us manage what we can measure, the same way we say we must do in business.

Our current business model in American health care is deeply embedded in one-fifth of our nation's macroeconomy: healthcare costs comprise $1 in every $5 of the U.S. economy. Without the patient-payer being the best, most engaged patient she can be, we don't have a prayer bending our cost curve or — dare I say — enchanting American patients. A key pillar of this vision-goal is liquid data under the control of patients, the new and ultimate healthcare payer.

GOING GLOBAL

OSCAR

OSCAR is maintained at McMaster University in Canada and used by over 1,500 physician offices with a 12% market share in the Canadian province of Ontario.[36]

`oscar-emr.com` ↗

Medic Mobile

Medic Mobile is an open source mHealth non-profit that trains community health workers (CHWs) to have impact on rural populations. Over 20,000 CHWs use Android-based phones and open source software to track immunizations, disease, antenatal care, and basic health in over 20 countries such as Kenya, Nepal, Uganda, India, and now in the Americas.

`medicmobile.org` ↗

iSantéPlus

iSantéPlus is sponsored and maintained by the International Training and Education Center for Health (I-TECH) at the University of Washington. Used at 115 hospitals and clinics around Haiti, iSanté contains over 700,000 patient records as of 2015.[40]

`www.go2itech.org/2017/05/health-information-systems-in-haiti` ↗

SIGA

The SIGA Saúde Health Information System in Sao Paulo (Brazil) is serving over 14 million patients yearly in over 700 health facilities, and stores records from 20 million patient contacts annually.[28]

`sigasaude.go.gov.br` ↗

OpenMRS

Supported by the Regenstrief Institute at the Indiana University School of Medicine, OpenMRS has a broad global appeal and is used in South Africa, Kenya, Rwanda, Lesotho, Zimbabwe, Mozambique, Uganda, Tanzania, Haiti, India, China, United States, Pakistan, and the Philippines.[35]

`openmrs.org` ↗

OPEN SOURCE HEALTHCARE HAS GLOBAL REACH

Creating, updating, and reconciling medical records is one of the most visible areas where technology has shaped healthcare. While most electronic health record (EHR) systems remain proprietary, over 30 countries now use open source EHRs in some capacity.[27] Founded in a rich legacy of global initiative to meet shared, human needs, successful open source healthcare IT initiatives are not only taking a hold in the United States,[32] but also spreading to Mexico,[28] Thailand,[29] France,[30] Uganda,[31] Zambia,[33] Kenya,[34, 35] Canada,[36, 37] Germany,[38] the UK,[39] Australia,[39] Haiti,[40] and many other societies.

openEHR

The openEHR was jointly conceived by University College London and Ocean Informatics Pty Ltd. Australia. Since its formal acceptance by the European Union and the International Organization for Standardization as CEN 13606,[41] openEHR is promoted by the openEHR Foundation comprised of 1500 members from 87 countries.[39] OpenEHR has been deployed in Australia, Brazil, the Netherlands, Norway, the Philippines, Portugal, Russia, Slovenia, Sweden, and the UK.[42]

www.openehr.org ↗|

DHIS

Developed in South Africa and supported by the Norwegian Government, the District Health Information System (DHIS) became the basis for the biggest open source health information system so far: The National Rural Health Mission is using DHIS, among other open source tools, to create a system serving hundreds of millions of patients in 18 of India's most populous states.[28]

ohie.org/project/dhis ↗|

AMPATH Medical Record System

Based on OpenMRS, the Academic Model Providing Access to Healthcare (AMPATH) Medical Record System (AMRS) was first deployed at the AMPATH center in Eldoret, a regional capital in Western Kenya, and then expanded to eight other AMPATH sites in Western Kenya.[34] The AMRS has recorded over 100 million discrete clinical observations from 2.8 million AMPATH visits made by 300,000 enrolled patients, from an eligible population of 2 million patients in the catchment area.[34]

www.ampathkenya.org ↗|

Hospital OS

Sponsored by the Thailand Research Fund, Hospital OS has been deployed at 95 small rural hospitals and 402 health centers serving at least 5 million patients in Thailand and Nepal as of 2011.[28]
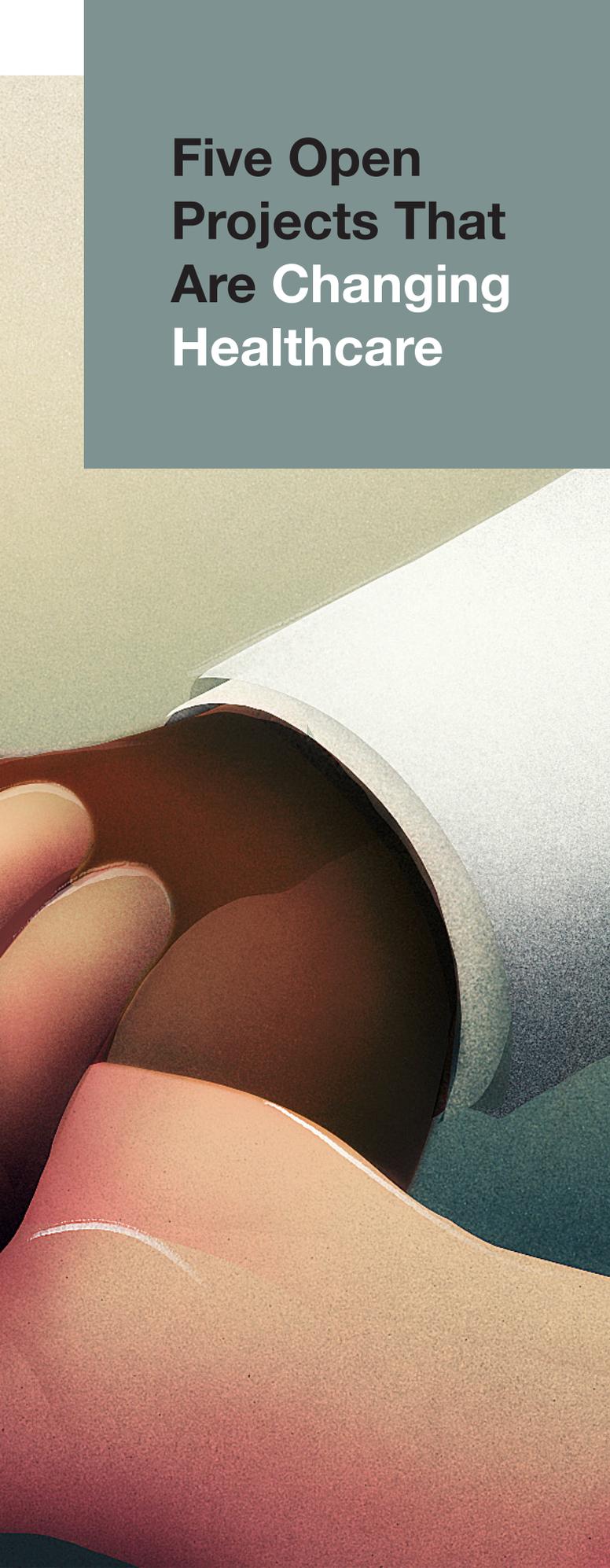
www.hospital-os.com ↗|

Open Hospital

Developed by Informatici Senza Frontiere, Open Hospital was first used at St. Luke's Hospital in Uganda and has since expanded to 23 sites in 13 countries serving over 425,000 patients.[31]

www.open-hospital.org ↗|

Five Open Projects That Are Changing Healthcare

FHIR

Fast Healthcare Interoperability Resources (FHIR) is an open source data format for healthcare. FHIR is developed and maintained by Health Level Seven International (HL7), a non-profit organization responsible for some of the most widely-adopted standards in healthcare technology around the world.

`www.hl7.org/fhir/summary.html` ↗

Open Humans

Open Humans is a platform that allows citizen scientists to share their health data in order to participate in research.

`www.openhumans.org` ↗

OpenEMR

An open source electronic health record system that targets small to medium-sized outpatient providers, openEMR is certified by the Office of the National Coordinator for Health Information Technology (ONC) to meet the 2014 edition of Meaningful Use guidelines in the US. OpenEMR enjoys broad adoption globally at over 15,000 healthcare facilities with over 45,000 practitioners serving over 90 million patients.

`www.open-emr.org` ↗

Sage Bionetworks Participant-Centered Consent

This toolkit aims to transform the concept of consent from a signature on a legal form to an inclusive process that educates and engages.

`sagebionetworks.org` ↗

Standard Health Record (SHR)

The Standard Health Record provides a single standard for patient health data at a national level.

`standardhealthrecord.org` ↗

UNDER ATTACK

Today, open source is under attack on a variety of fronts and it is losing the fight. Corporations are actively discouraging open source participation through a number of means. Worse yet, the grey area between civic and corporate power is ratcheting up cynicism and driving down engagement in the OS community.

Companies are prohibiting their employees from pursuing outside-the-firewall technical work as a condition of their employment. Such "extra-curricular" activities are critical to playing with, experimenting with, and learning from new ideas, as well as being an engaged open source community member. These constraints go far beyond the standards of non-compete rules: "No unauthorized or external work, regardless of domain, if you work for us fulltime!"

The internet infrastructure has matured and is moving further away from its origins. What once was built with public funding (as a military research project), that evolved through public-private relationships (fiber lines and cell towers), and thrived on open sourcing (Tim Berners Lee's Hypertext) has now become the commercial domain of the Googles and Amazons of the world. Our internet's infrastructure is moving from distributed to centralized services.

Companies are discouraging interest in open source by actively propagating the false and unsubstantiated myth that open source doesn't generate profits.

We're dismantling a fundamentally democratic system of management in favor of corporate-oriented governance and oversight. Prime examples are the elimination of net neutrality and the shift of the FCC's allegiance from public to corporate interests, which advanced the expansion of "walled gardens" like Amazon and Alibaba.

OPEN SOURCE HEALTHCARE MISSIONETTE

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 blackbox 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.
The crooked biases built into software,
implemented with intent or accidentally,
need interrogation, citizen collaboration, and correction.

It's our health.
Our very lives are at stake.

We demand that our healthcare services be open
to inspect and correct bias,
to be accessible for rapid innovation and evolution,
and to become more valuable as
more patients, clinicians, clinics, companies, and
governments engage in healthcare for all.

Nine Organizing Principles
of Open Source Healthcare

1. Simple National Standard

Establish, maintain, and evolve a single, national target for health data standardization. This common data element definition for human health will be available under a business-friendly, open source license (such as Apache). It's open to any interested party, organization, or individual both domestic and international.

- Contributors will be vetted by the model stakeholders.
- No single party may have exclusive rights to the schema.
- Major changes to the standard must involve an open decision-making process and a consensus between all stakeholders.
- The standards must be managed by an official, elected organizing body for a term of 4 years (with a term limit of 8 years).

2. Cost Transparency

Prices for healthcare services, from medical treatments to insurance costs, are publicly known and posted. Cost transparency promotes patient choice.

3. Responsible Use

Criminalize the unethical and wrongful use of personal healthcare data.

4. Data Usage Transparency

Every update or change to a patient's healthcare record requires a healthcare receipt. After an encounter, a receipt detailing the conversation and collected information is sent to the patient and corresponding care team.

5. Transactional Care

Patients have the rights to see who, what, where, when, and how people and services use their healthcare data.

6. Own Your Data

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.

7. Share Your Data

Patients are free to use personal health data in any legal way they choose and free to share some or all of their personal health data with whomever they choose.

8. Health Data as a Public Resource

Provide access and development tools to public health data for scientific research and acceleration of scientific discovery. Allow patients to share or donate any part of their data, either as de-identified or real data, to science.

9. Community Engagement

A national health literacy service drives adoption of health data models and engages the imagination of the public to understand patient rights and health policy.

A framework for responsible use and management of patient health data and information for the advancement of health quality, health research, and data ownership
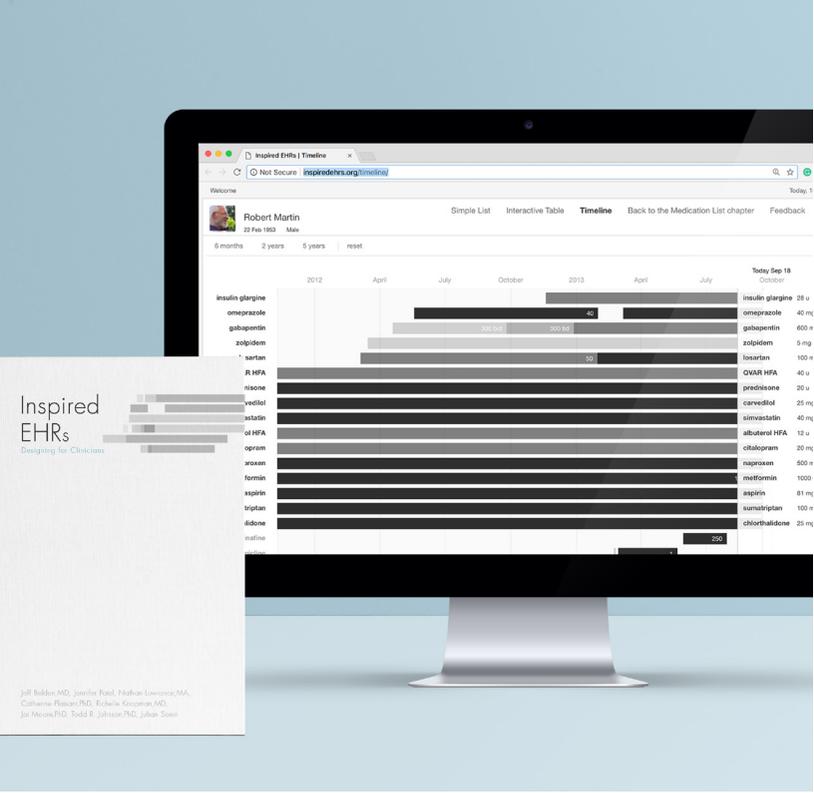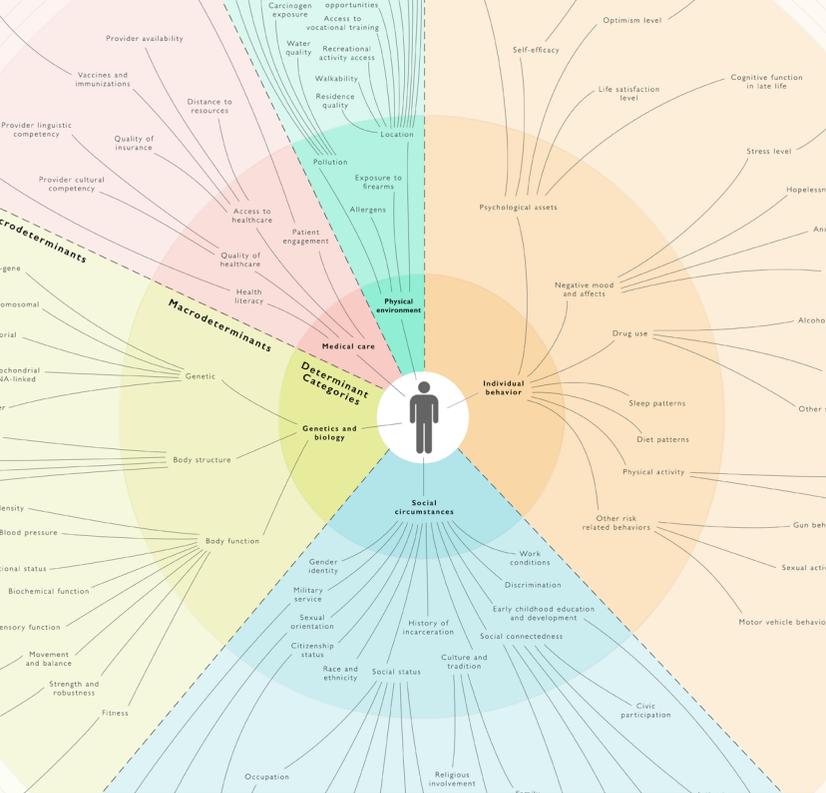
Determinants of Health

A visualization of the determinants of health, to be used as a vehicle within health organizations to drive the concept that health is a holistic measurement of one's entire life.

determinantsofhealth.org ↗

Inspired EHRs

A collection of useful and usable Electronic Health Record (EHR) interface designs accompanied by insights and interactive examples, guided by basic design principles.

inspiredehrs.org ↗

hGraph

An open source javascript-based web application for visualizing health data.

hgraph.org ↗

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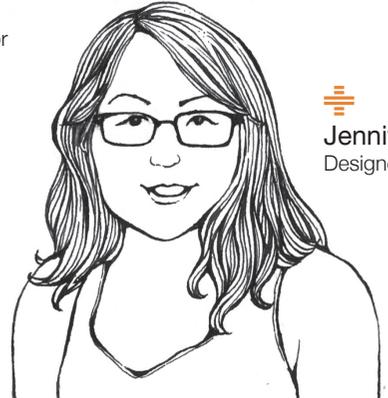
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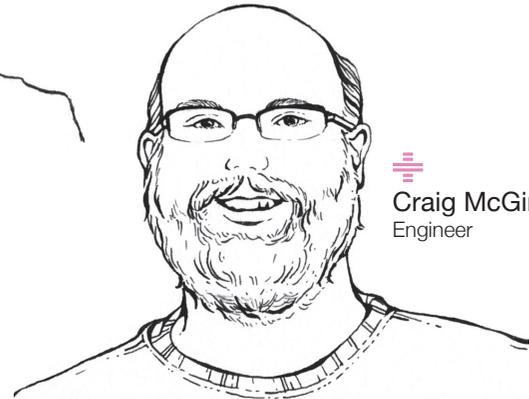
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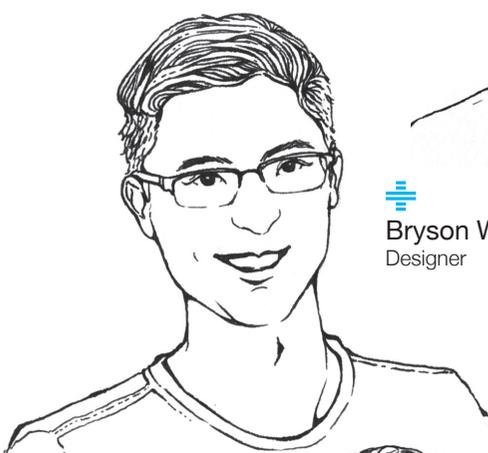
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