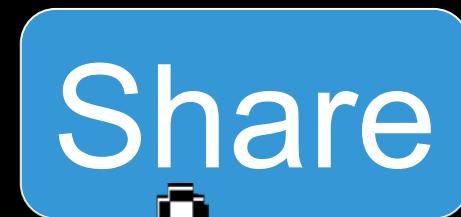


A hospital Share button?



Steven Keating
Astrocytoma patient

Personal thoughts on APIs, presented on Jan. 28, 2016
Contact: stevenk@mit.edu Website: www.stevenkeating.info

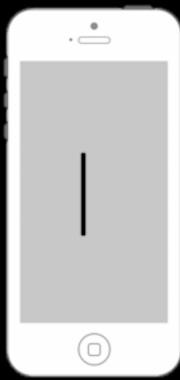
Over 650 billion photos uploaded per year



For ages 18-24:

30% are “selfies”

Over 1.5 million apps for iPhone



Average app price is \$0.19

90% are free

Over 38 million articles on Wikipedia



60x bigger than 2nd largest encyclopedia (Encyclopedia Britannica)

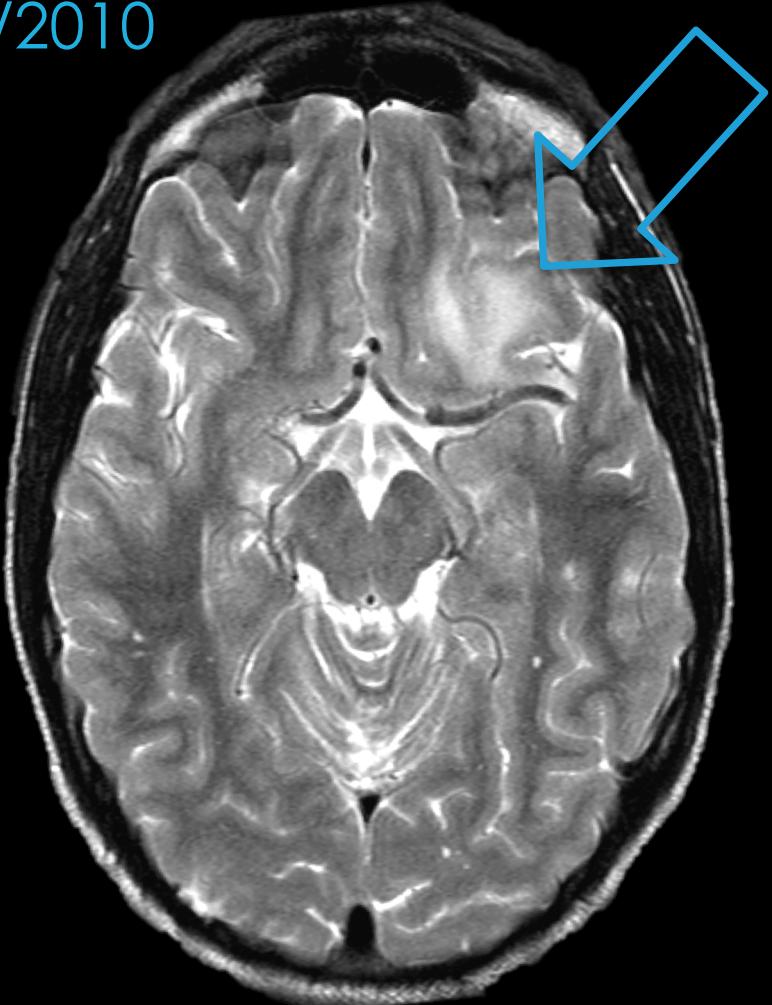
Created by all for all

Why hasn't healthcare caught up?

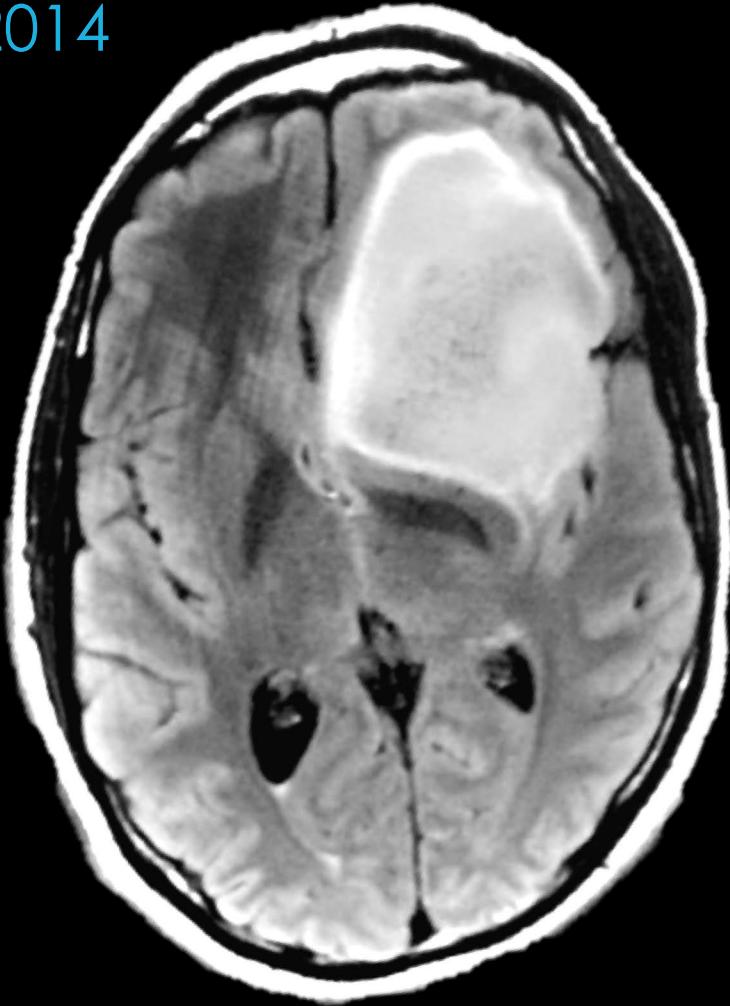
Fax machines, mailed CDs
Constrained patient portals
Lack of tools and standards
Legal gray zones
No translucency

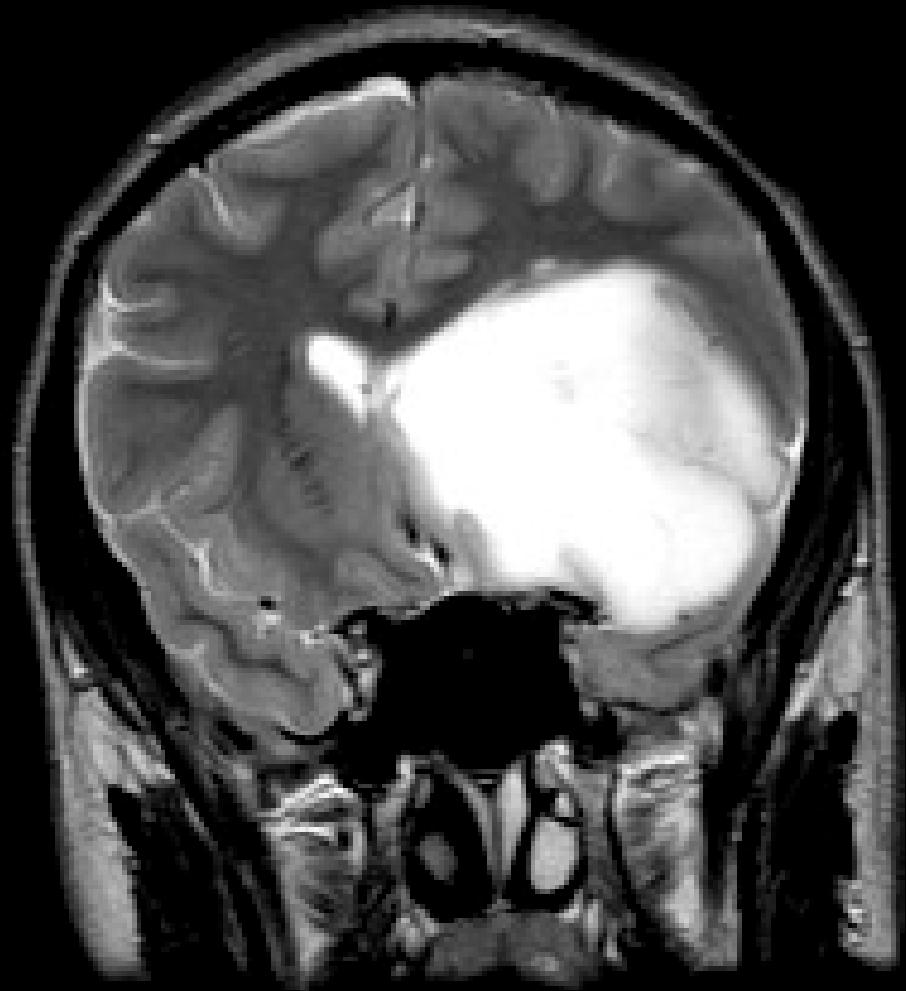
Access to my own data from a
research study helped save my life.

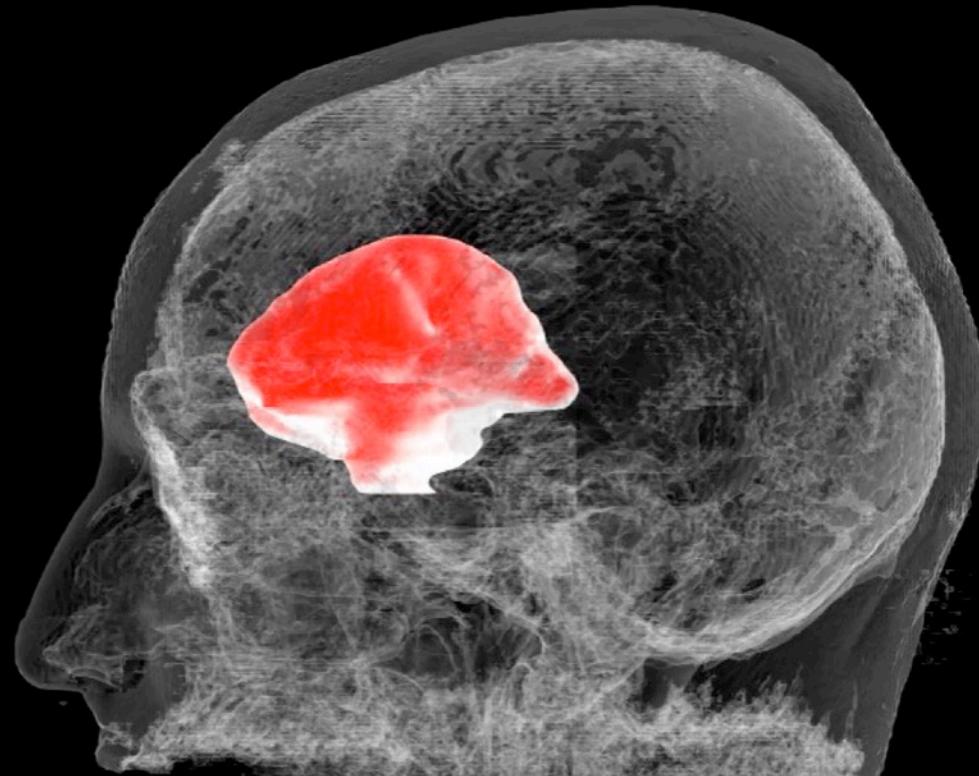
2007/2010



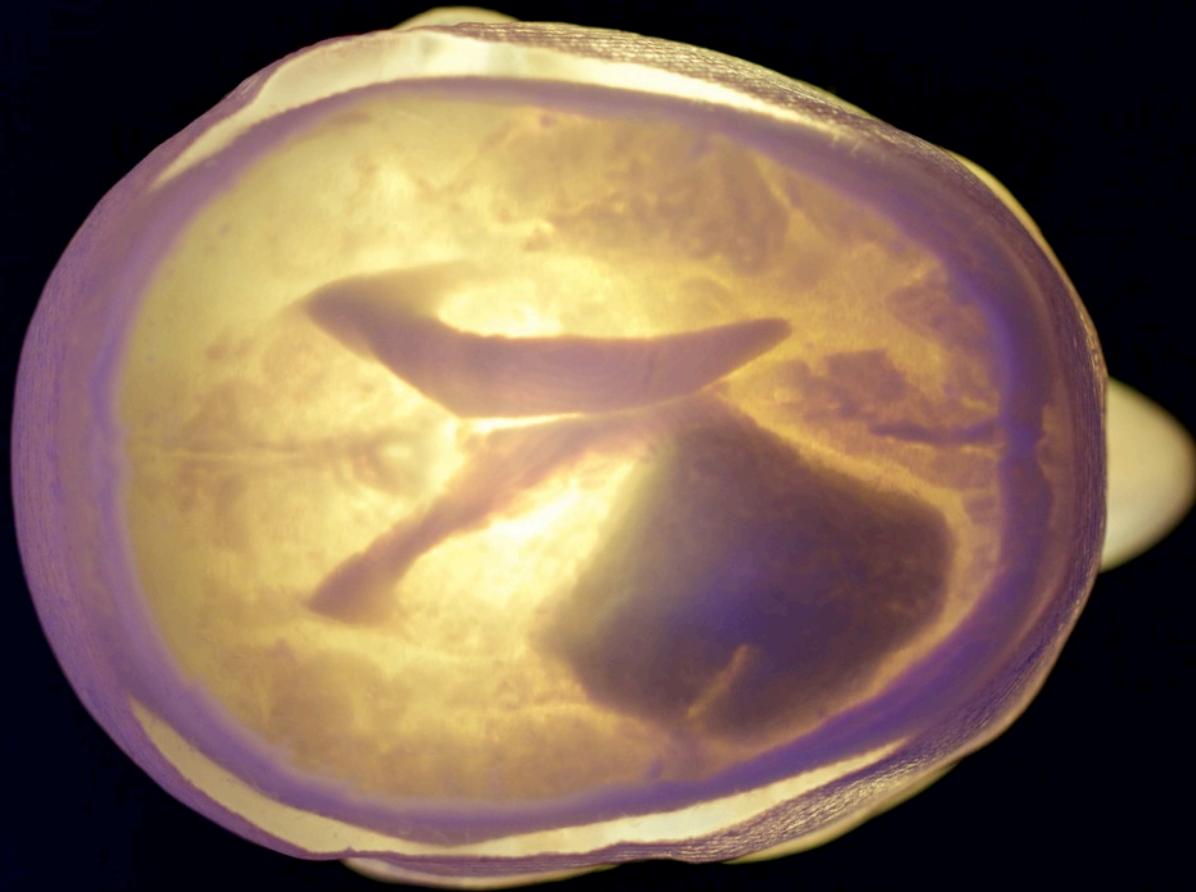
2014

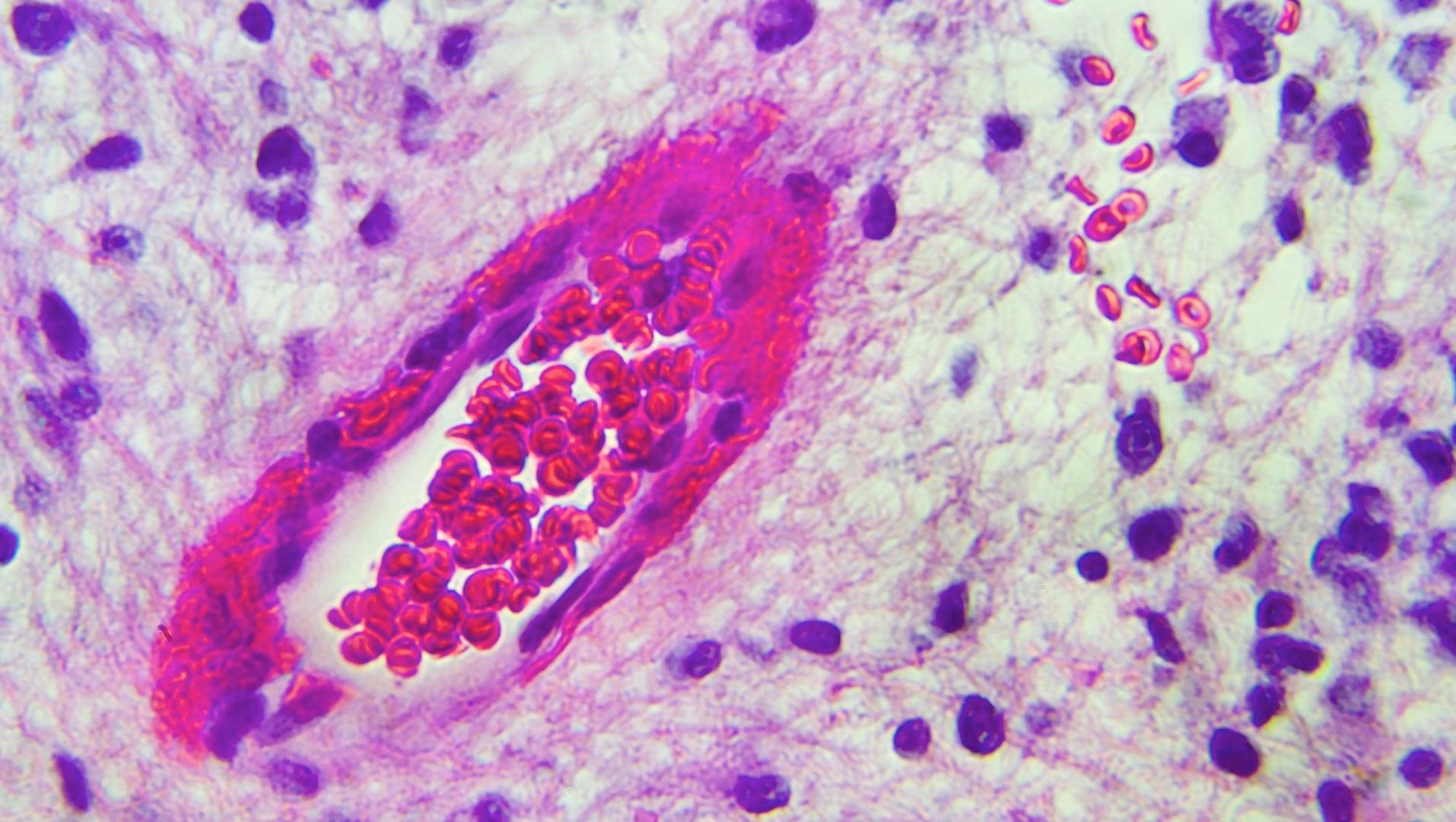














- Pre-surgery data (MRIs, blood work, and more)
- Video of the surgery
- Genetic data (IDH1, P53, MYLB1, NF1, SDHA)

- Post-surgery monthly imaging

- Microscopy of tumor tissue

- 3D computer analysis

- Multidisciplinary printing of biomaterials

- NHC spectra comparison

- Microbiome analysis during chemotherapy

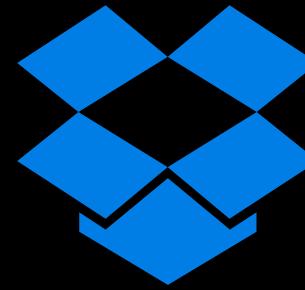
- Proton scan data

- Neural test results

- Endocrinology test data

200 GB

Why don't these tools exist



for **health?**

home

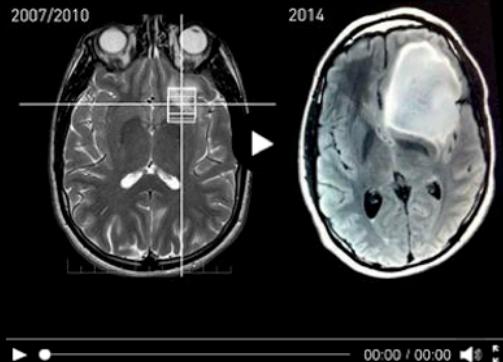
back

contact

fighting cancer through curiosity

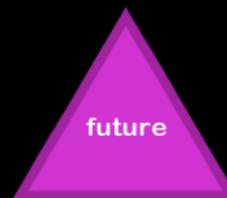
In August, 2014, I was diagnosed with a baseball-sized IDH1 tumor (astrocytoma). I was asymptomatic until then and given three weeks before a 10-hour awake brain surgery. But the story dates back much further, to 2007 when I was merely curious about viewing my own brain in a voluntary academic scan and had accidental findings. Science and curiosity have saved my life. I am writing this with a hole in my brain, roughly 12 trillion synapses! I want to enable other patients to collect, understand, and share their data. I am a strong privacy proponent - I believe patients should have the choice and control of their own data.

For more information, to the right is a 10-minute recent talk I presented at the MIT Koch Institute ([YouTube link here!](#)) as well as a couple articles on my



[click here to download my brain tumor and more!](#)

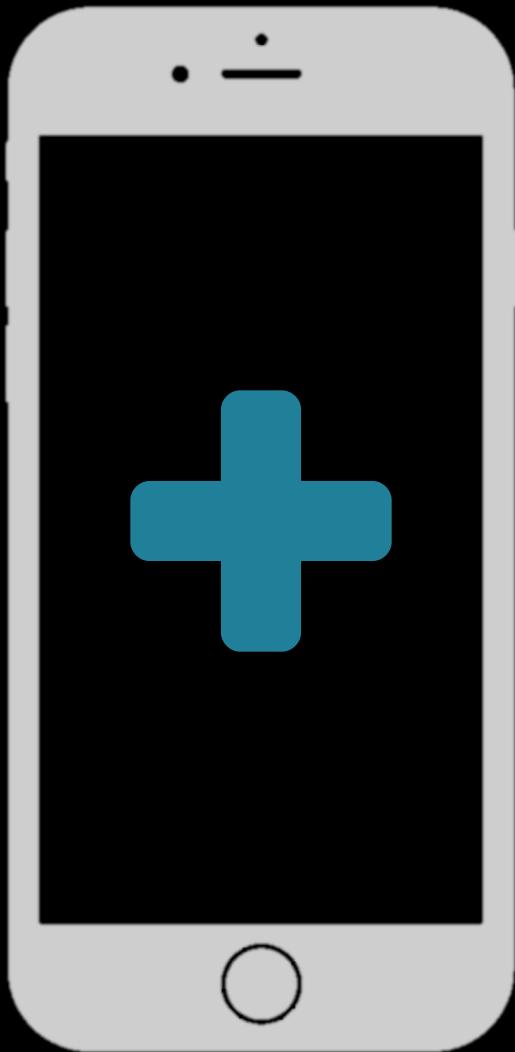
(ok, I know that's an odd phrase to read...but at least it's interesting?)



steven keating, 2015. steven keating's personal health data posted on this website is released under CC0 (creative commons).

Leverage **curiosity**

If even only 0.01% of Facebook's 1.5 billion users shared a component of their health data, it would be one of the largest medical studies conducted.



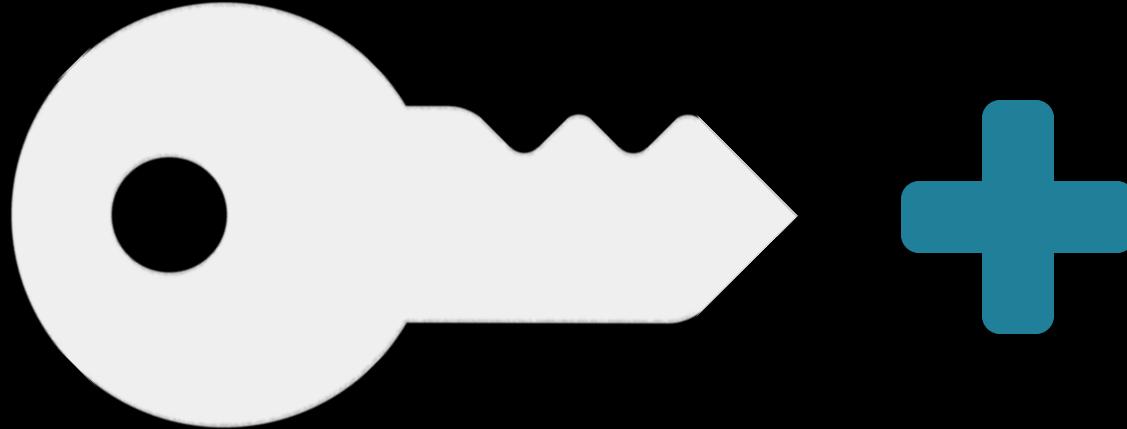
Apple ResearchKit

First week: 50,000+ users

Over 75% of users shared their data with researchers



- ~99% of patients wanted continued open access after one year.
- ~80% would impact their future choice of provider
- ~70% reported taking better care of themselves.



We need an open API under patient control.

Simple to use, remove low barriers

Standardized, open to 3rd parties

Patient controlled, full access to raw data

Enable research data and patient-submitted data

Better measurement tools for API compliance

Data generates support.

Support is medicine.

We need to fund more research around quantifying effects of sharing medical data – benefits/risks to patients, to communities, to doctors, to providers, and to researchers.

Detailed thoughts for API policy:

- Ensure easy, standardized access that is simple for patients, doctors, researchers, and code developers. Not only access, but the ability to send data to 3rd parties, download apps, and submit data themselves.
- Allow for new types of data through developer-defined resources within a standardized template.
- Accommodate research data in simple and easy to use manner. Need to allow aggregation of data that the patient can control and share at their own choice. Show the incentive to researchers of APIs allowing direct-to-patient studies, sourcing participants through apps for trials, and having dynamic relations where more longitudinal studies can occur.
- Classify a difference between raw data and analysis. Patients should always have access to their own raw data (without IRB). Analysis should have some type of IRB approval process (aka hospitals to verify apps, like Apple with app store) to facilitate people finding apps they can trust.

Detailed thoughts for API policy:

- Allow patients to make decisions if they understand liabilities – e.g. Personal Genome Project's test for liability understanding before genome sharing is allowed. While an IRB process is necessary for apps approved by hospitals, API toolsets should be available to all developers, and adventurous patients who understand the liabilities should never be limited to access or send their own medical data.
- Don't structure APIs around worst-case scenario patient + security risks – each patient is unique and should be allowed to make their own choices. Look at HIPAA, CLIA, and the Common Rule – all supposed to help patients, though all have been barriers (and scarily enough, even the new Common Rule proposal encourages banning patient data access for secondary research by a suggested IRB exception – see my comment letter here if interested in more details: <https://t.co/NL6RzqAmhC>). Try to clarify these policies to ensure they are conflict-free (example, I still can't access my own brain tumor's whole genome, as the study was done on a non-CLIA machine, even though my doctors + the researchers want to give me back the raw data and I want to share it with the world to advance research). Empower patients to make their own decisions.

Detailed thoughts for API policy:

- Incentivize app-developers to ensure there are a handful of user-friendly, exciting, innovative, and novel apps ready to go when APIs launch. Apps for simple and quick things – generate a medical “selfie”, donate your blood chemistry and get listed as an author on a paper, download a free bio textbook that uses all your own tissue images from the pathology lab, donate your MRI scan and receive a 3D printed skull bottle opener for free! Fund or incentivize easy access for health “hackathons” at schools to inspire the next generation of coders.
- Look and connect with existing successful companies who have large APIs, such as Twitter, Facebook, and Amazon Web Services. Speak to folks working on successful health API examples such as Open mHealth, Human API, Fitbit, and 23andMe. Talk to companies developing current systems to get around patient portals, such as Picnic Health and Gliimpse, and to companies/non-profits organizing large amounts of open patient data such as Sage Bionetworks, Cancer Commons, and PatientsLikeMe. Report these results publically, we need to quantify the potential benefits/risks.
- Think globally – look at examples in other countries and explore standardizing across borders.

Detailed thoughts for API policy:

- Look at new standards emerging for healthcare APIs such as FHIR and ensure that the large companies who control medical record software, such as EPIC, will implement these new open standards.
- Most importantly, make an effort to educate the public. It was a complete surprise to me how broken the system was for patient data access, use, and sharing in hospitals. People only find out when they are the patient, and in those cases, the lowest barriers are mountains as folks are just trying to stay alive and get out of the hospital. We need to inform patients how valuable their data can be – to themselves, to their family, and to the world through research. We want folks to see the value, to be incentivized to join new research studies, to make informed decisions to improve their own health, to share their results and become partners in their own care. Without this critical need for patients to see the incentives, the adoption and use will be problematic. Instead of being last in line to their own data, patients need to be put first and they will drive the change forward.