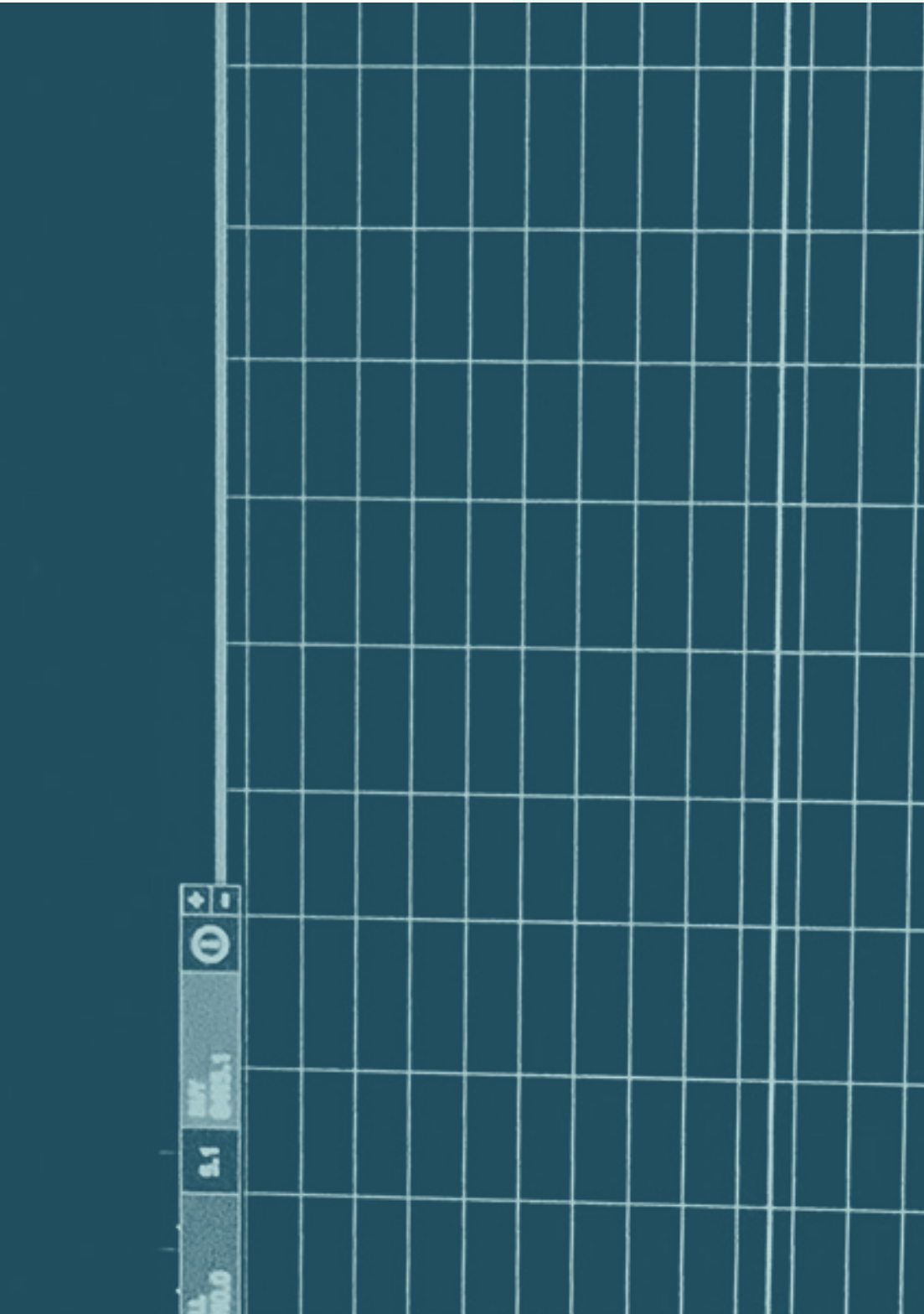


# Taking Care Of Data



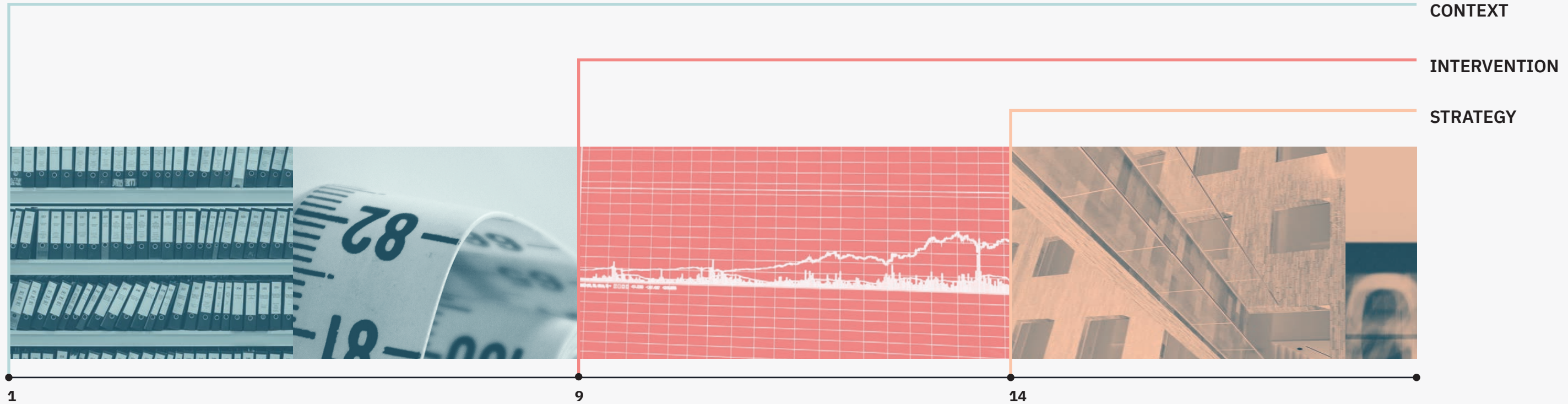
Empowering the Patient through ownership and understanding of their health records and data generation within the US health care system.



Recently much of the public conversation in the news and media explores how ownership of personal data is defined; especially in the capital market. This is seen through national policy (General Data Protection Regulation, EU), multiple lawsuits (FB & HUD), and publicly broadcast Supreme Court hearings (Facebook 2018).

This project aims to apply questions of data ownership to healthcare focusing on the patient's relationship with their individual data. Do the policies and solutions to the free market apply personalized, data? How can the patient be empowered in their own health literacy without being exploited for the interests of the stakeholders at large? Should healthcare be classified as a "market" or is this commodification of service counterintuitive to the care that is provided? How might the lay person record and use their personal data to better understand health risks and diagnosis? And how might the primary care physician advocate for the careful use of data?

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# Context



## Electronic Medical Records

Currently there are 6,210 hospitals in the United States. Each is responsible for the documentation and data entry for each of their patients. The sheer amount of data is something quite incomprehensible, however the value of this data comprehension is integral to each patient's diagnosis made by the doctor.

In primary care, the storage, entry, and sharing of this of data is stored mainly within **Electronic Medical Records (EMR)**. The Records are stored and retrieved during a patients visit. This retrieval process becomes quite difficult as physicians struggle with efficiently reading, comprehending, and communicating the

**The software “has created this massive monster of incomprehensibility,”**

–Susan Sadoughi, Primary Care Physician

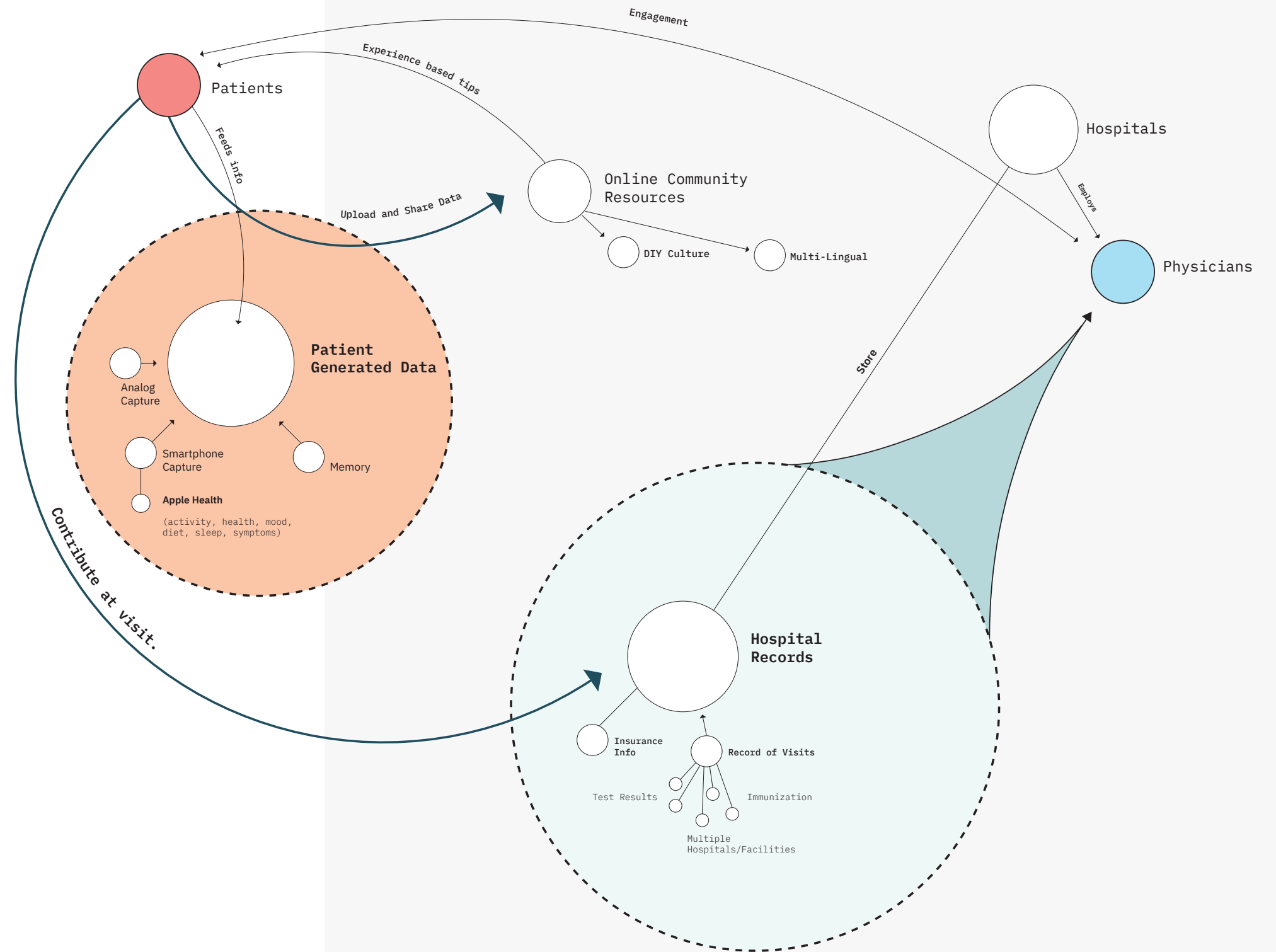
information to the patient within the span of the hour long visit.

Epic Systems Corporation is an private EMR company supplying **record keeping for 54 percent of America's patients and 2.5% of patients worldwide.**

Susan Sadoughi, a primary care physician describes the Epic system in a New Yorker article as a “massive monster of incomprehensibility.”

# Knowledge Transfer Ecosystem

In order to understand the complexity in the Electronic Medical Record field, an ecosystem of entities within the field of “health knowledge transfer” was crafted including how each entity flows and relates to another. This map is made up of entities surrounding both the Patient and the Primary Care Physician and includes macro levels of data sharing and storage. The Diagram illustrates a distinct **separation of Patient Generated Data and Hospital Records**.

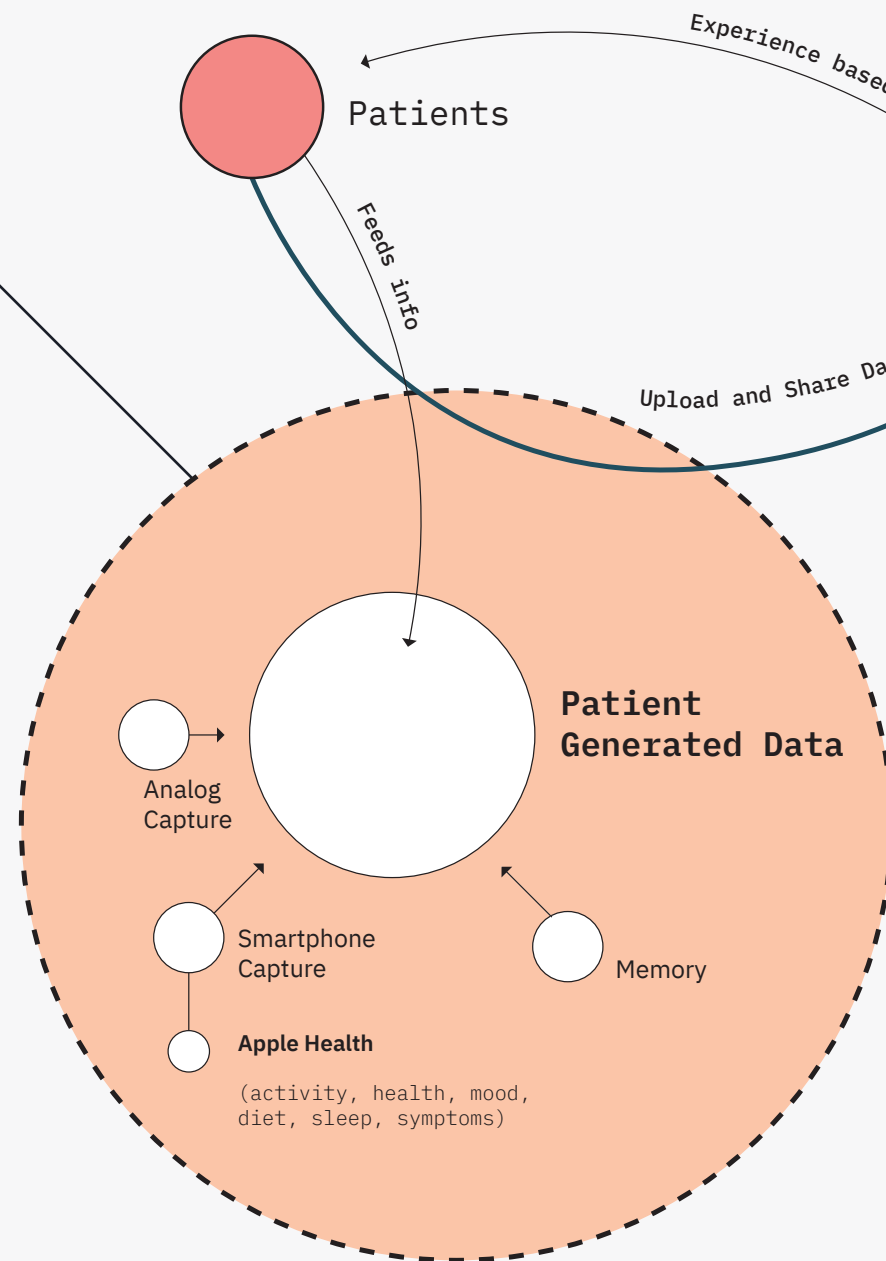


# Patient Generated Data

In clinical practice patient generated data exists in forms of hospital records, insurance info and visit records. However the data from other capture methods are not currently being used in this area. **How might the doctor facilitate the capture of usable patient data?** Or is it the patients responsibility to collect and display their own data to their care provider.

**“Step counts! Oh, if we just had step counts.”**

– Neil R. Malhotra, neurosurgeon University of Pennsylvania



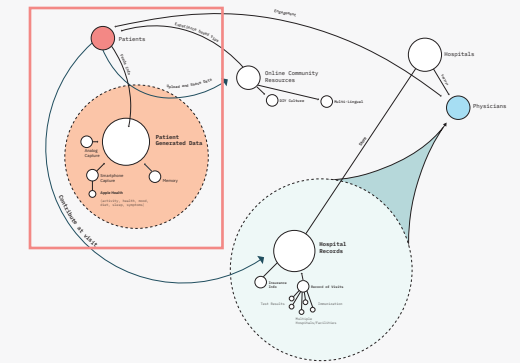
# Online Community Resources

Some patients use online communities, such as Twitter groups, to seek answers to questions their doctors aren't addressing. The online presence offers support to its members because each member made up by someone with a direct connection to the topic issue.

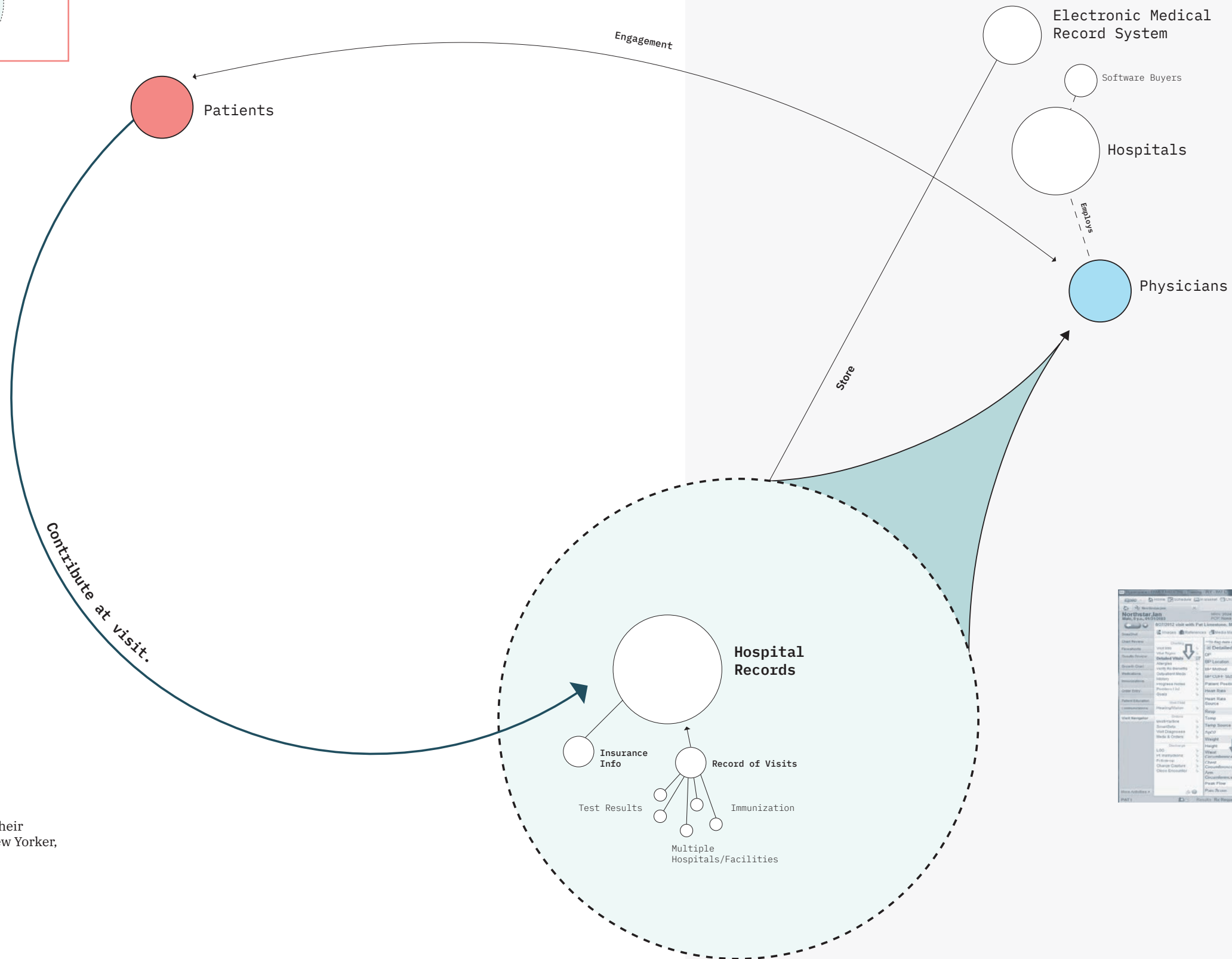
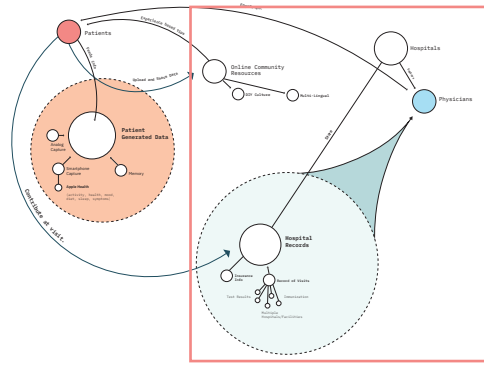
Moderators of the communities validate the treatment recommendations. In 2006,

## How “valid” should you assume your diagnosis?

researchers at the University of Texas analyzed the content from a breast cancer forum for medical accuracy. They found that 10 of the 4,600 postings contained false information. 7 of these posts were deleted



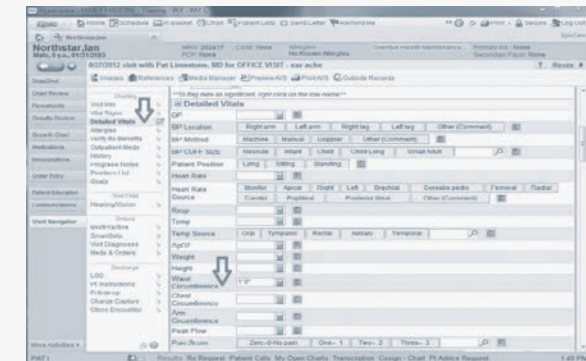
leaving only 3 of the 4,600 posts to slip by uncorrected. (Suzanna Fox)



# Data Overload

The amount of information a doctor must digest and interpret within a visit is extraordinary. The doctor must do this within a 30 minute doctors visit and a lot of the visit includes the doctor just reading and explaining the collected data out-loud to the patient as well as their own understanding.

The Epic System is used by UHealth. This is screen-shot of what a typical patient chart looks like. Speaking to Dr. Williams, a University of Utah Hospital resident, he explained how hard it is to navigate this system and how much practice familiarizing with the software is needed.



Gawande, Atul. "Why Doctors Hate Their Computers." The New Yorker, The New Yorker, 24 Apr. 2019,

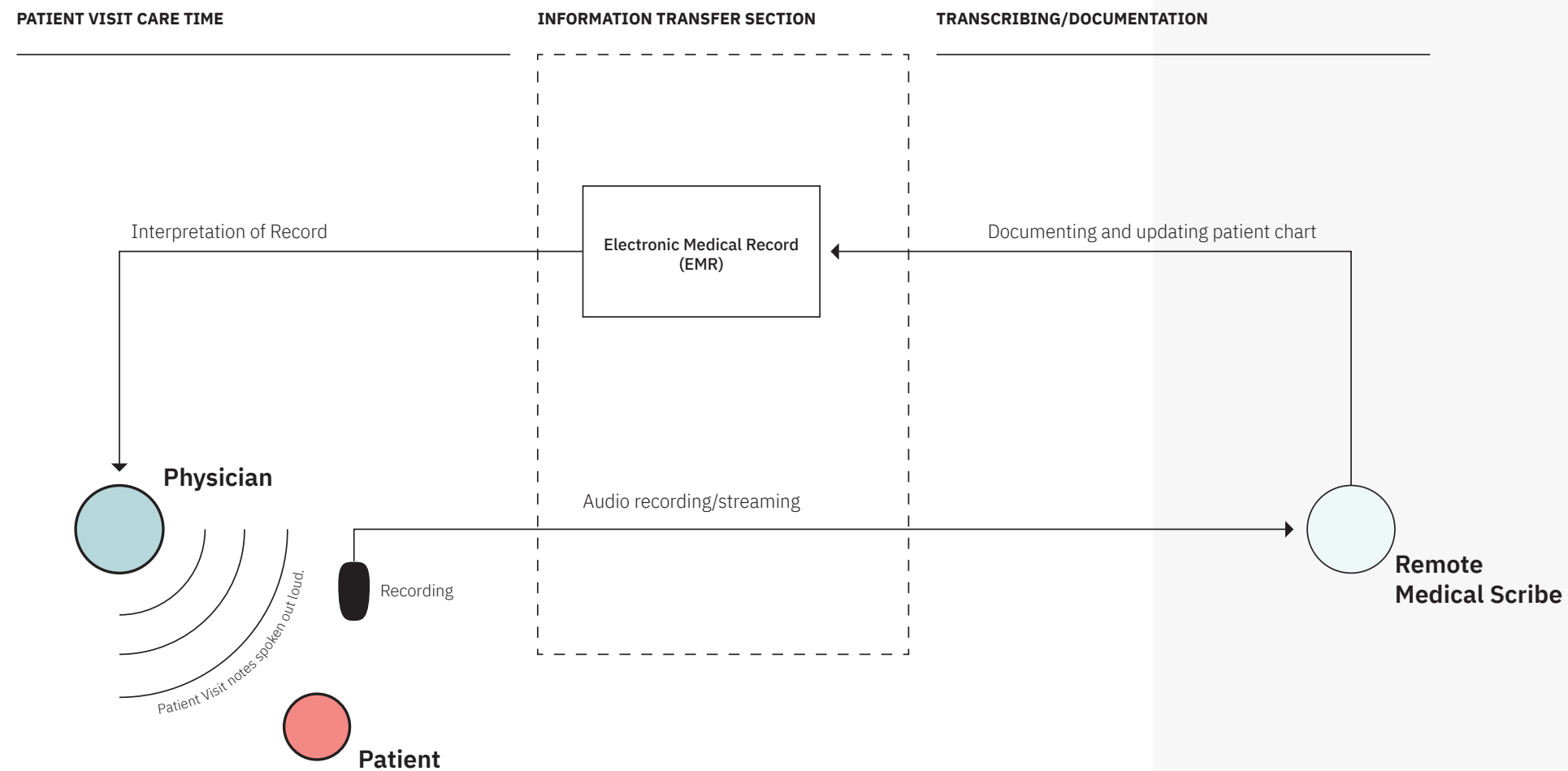
**One hour with  
a patient means  
two hours of  
entering data.**

Twachtman, Gregory. "Study: One Hour with Patients Means Two Hours on EHR." CHEST Physician, 3 Apr. 2019,



# Team Documentation & Medical Scribes

## Team Documentation Process



One intervention to the sharing of data is the area of Medical Scribes. A Scribe sits in physically or digitally to a patient visit and is solely responsible for the electronic notation of the patients chart. This frees up the physician to interact solely with the patient without bouncing between the patient and the electronic chart.

This works by using “Trigger Phrases.” When the doctor says something like “**Your exam is normal except for...**” this signals to the scribe that a not should be taken.

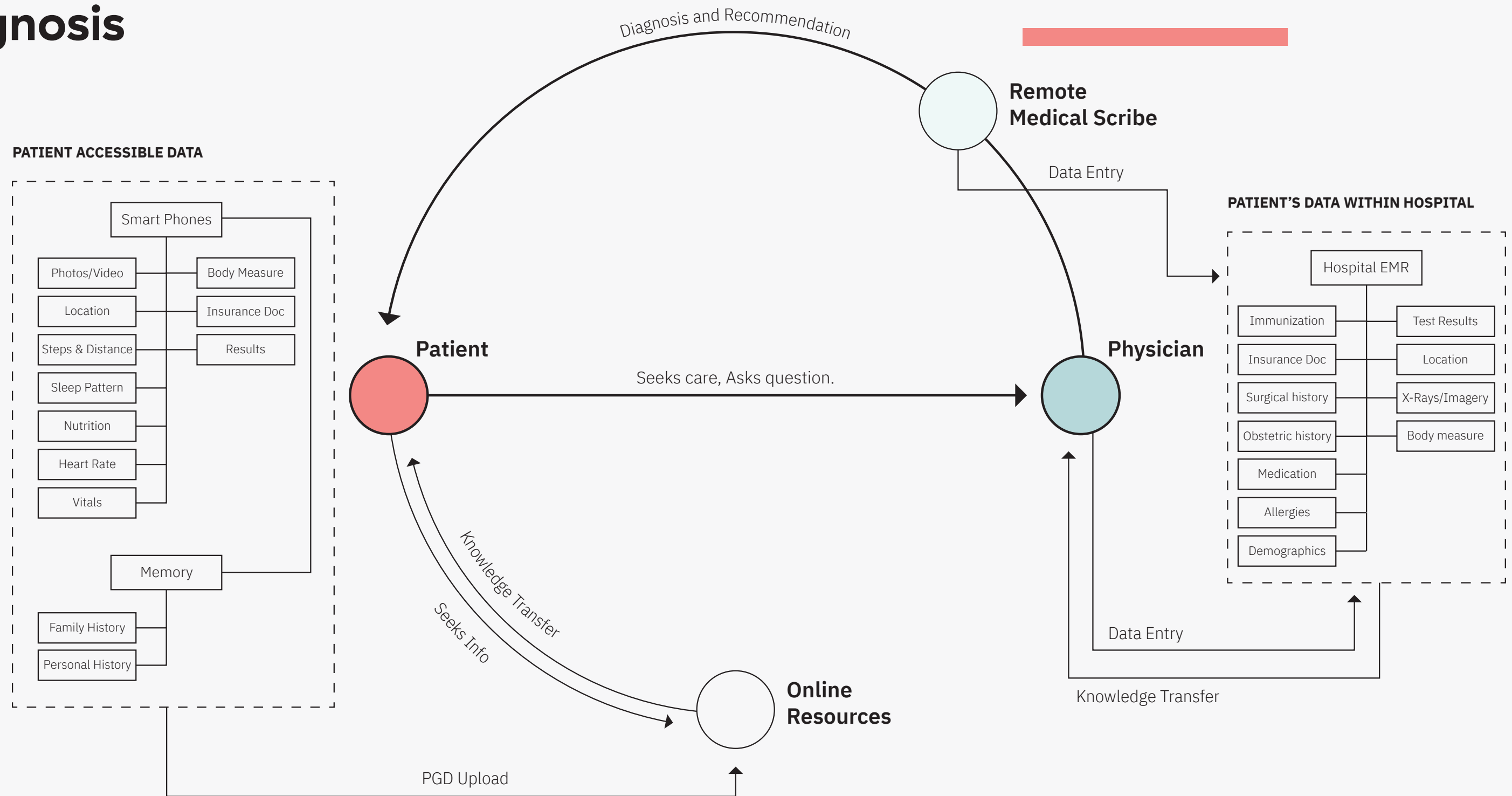
Now with advancing technology, with the patients permission, visits can be recorded with a multi-directional microphone. Then encrypted and transmitted through the Internet to a scribe overseas. The scribe makes notes to the health system and updates the patients file.



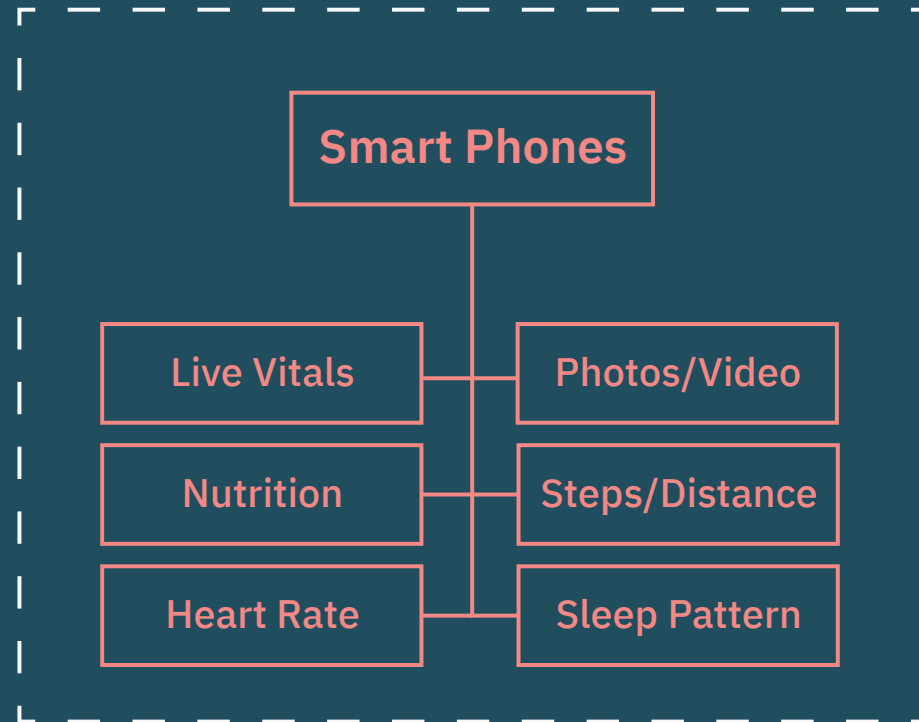
### Intervention Space:

**Robin AI is a Artificial intelligence** made for physicians. The device can record audio and video and takes notes for patients file. Messaging on website: Technology that Doesn't Interrupt Care.

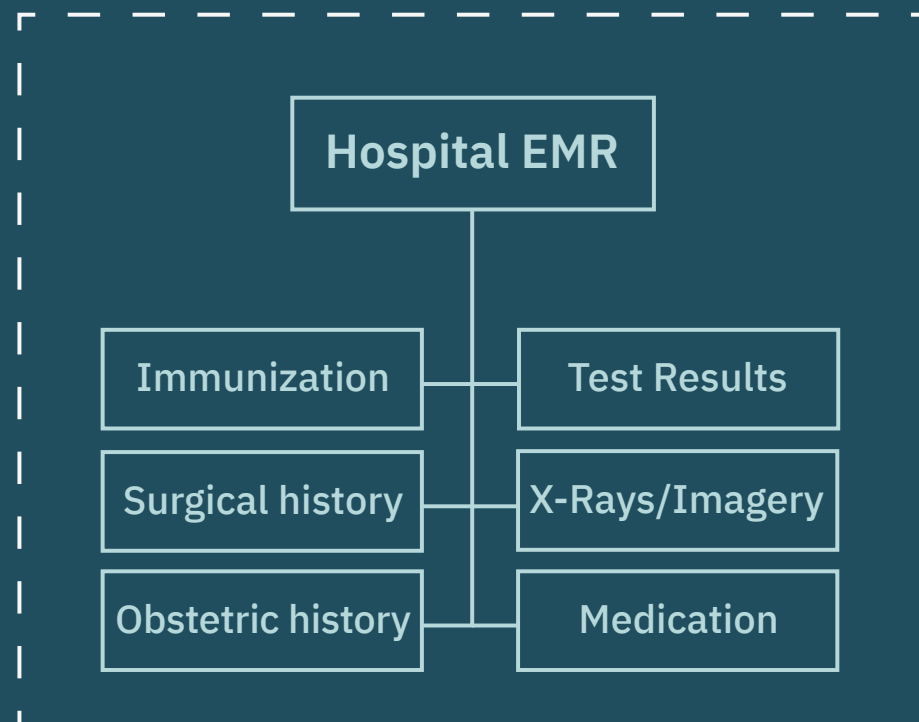
# Data Dynamics in Patient/Physician diagnosis



## PATIENT ONLY DATA



## PATIENT'S DATA WITHIN HOSPITAL



# Data Access

The diagram above separates types of data that is only accessed using smart phone PGD and data types only accessible through the hospital system. Its important to note that much of the data on the right may be recorded in a smart phone, but the inherent procedural data is established in the facility of care. (Surgical, Immunization)

A Study in JAMA Network Open explores the difficulty of getting access to one's Medical records. Dr. Harlan Krumholz, director of the Center for Outcomes Research and Evaluation at Yale New Haven Hospital in Connecticut, had trouble getting records for a family member so they decided to study the setbacks to record retrieval.

Krumholz examined 86 of the highest World Report ranked hospitals and explained to them that her grandmother was recently treated. She asked the hospitals a series of questions:

- What was the procedure?
- What was available?
- How long would it take?
- How much would it cost?

Of the 86 hospitals, 29 listed exact costs on a request form on their web page, 1 offered records free of charge, 18 said there would be a charge of some kind, and 36 didn't specify.

Costs on forms ranged between \$0.00 - \$281.54

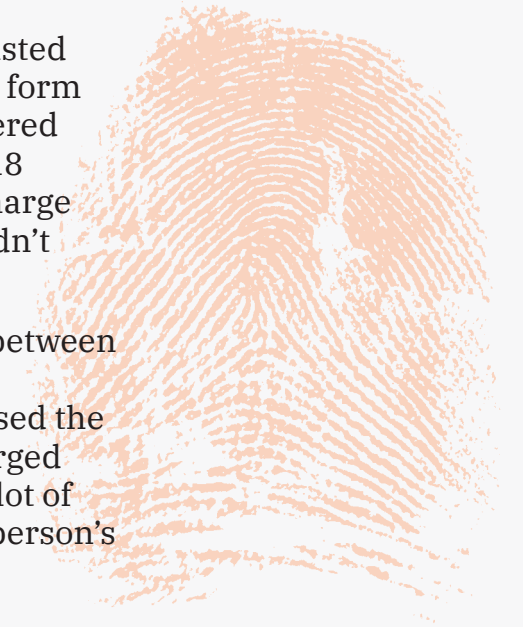
On the phone, 82 disclosed the cost. One hospital's charged \$541.50. This is quite a lot of money for records of a person's property under HIPPA

### Krumholz argues:

"But we don't need to lobby legislators in Washington for this," he said. "The law is clear. We need to get health systems in compliance with the law."

### Ask Yourself:

**Do I have access to my medical records?**



# Current Interventions

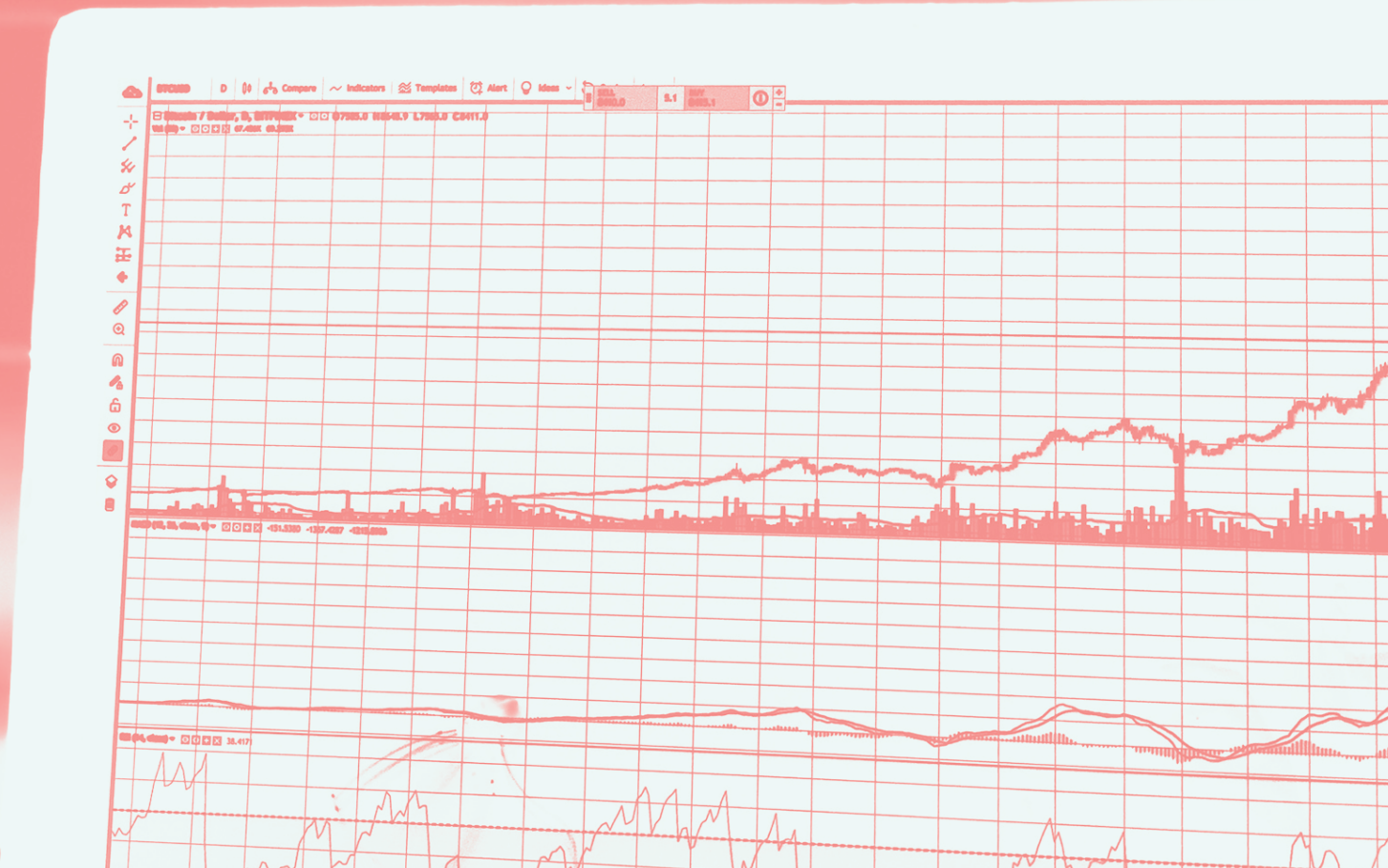


Table 1: Online health seekers  
Among 14-22 year-olds, percent who have gone online for information about:

Fitness and exercise	63%
Diet and nutrition	52%
Stress	44%
Anxiety	42%
Depression	39%
Birth control	30%
Pregnancy	28%
Sleep disorders	27%
Sexually transmitted diseases	26%
Drug or alcohol abuse	24%
Cancer	24%
Smoking	20%
Eating disorders (such as anorexia or bulimia)	18%
Diabetes	16%
Heart disease	14%
Any other mental health issue	6%
Any other physical health issue	6%
TOTAL – any health topic	87%

## Digital Presence

87 % of 14-22 year olds have gone online for medical advice. The top three categories of interest being:

1. Fitness and exercise
2. Diet and Nutrition
3. Stress and Anxiety

The internet is becoming a place to seek diagnosis. These top three categories of information become apparent in Mobile Apps. Each using their own system to capture and use personal data.

This section will examine the current interventions of the digital space and personal health data. What is working? How? And What might work better?

(Rideout, 2018.) Digital Health Practices, Social Media Use, and Mental Well-Being Among Teens and Young Adults in the U.S.

# Intervention Review

Looking at the Current interventions and the messaging/marketing language we see several themes arise:

- **“Personal Health Narrative”**
- **“Open Source Software”**
- **“Symptom Checker”**

These interventions rely heavily on the capture and usage of patient generated data. Here some quotes are shown explaining the user’s experience with Digital Health technology.

## Human Intervention Quotes:

### + 01 DIY Diabetes

“Medtronic insulin pumps to receive external commands, Lewis and Leibrand were able to connect a Raspberry Pi, a small single-board computer running custom software, between her CGM and one of these hacked pumps, effectively closing the loop for her as of December 2014. “Once I had it turned on, tested, and working,” she wrote later, “it was hard to convince me to take it off.”



### + 02 HopeLab’s Research on Digital Health

“The app I like to use is a period tracker. It also gives facts about symptoms you feel throughout the month. It’s helpful because whenever I’m feeling a certain way and not sure if its period related I always go check how many days till my cycle and it usually makes me feel better.”

– 17 year-old female

“[A meditation app] was real cool, it helped me refocus and understand awareness.”

– 20 year-old male

“I have an app that basically gives you a bit of inspiration every morning to be you and love yourself. It helps me take time for me instead of rushing around at 6

in the morning stressing about the day.”

– 14 year-old female

“My favorite health related app is [one on addiction and sobriety]. I’m bulimic and it helps me try and stop bingeing and purging.”

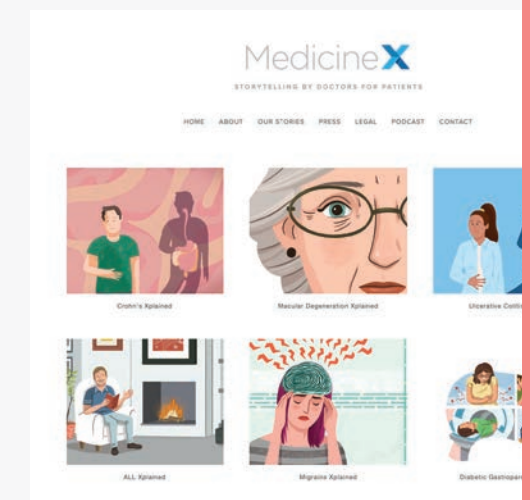
– 22 year-old female

(Rideout, 2018.) Digital Health Practices, Social Media Use, and Mental Well-Being Among Teens and Young Adults in the U.S.

### + 01 MedicineX

“Medicine X works with a team of illustrators, writers and designers to create vivid and engaging stories. The ability to capture details that make up the life of a real-life patient is critical in the story telling process, and this is why Medicine X only works with the most talented artists.”

“Each of our stories are created to be simple, interactive and easy to understand. No medical jargon. No “doctor speak.” No complex descriptions; just easily understandable information that is accessible for all.”



# The Issue with Health Apps

“Symptom Checker”  
 “Diagnosis” “Created by top Doctors” This is the messaging popular in the top grossing Health data apps. The issue here is that the usage of these apps can come with hidden terms of use that can compromise the user’s privacy.

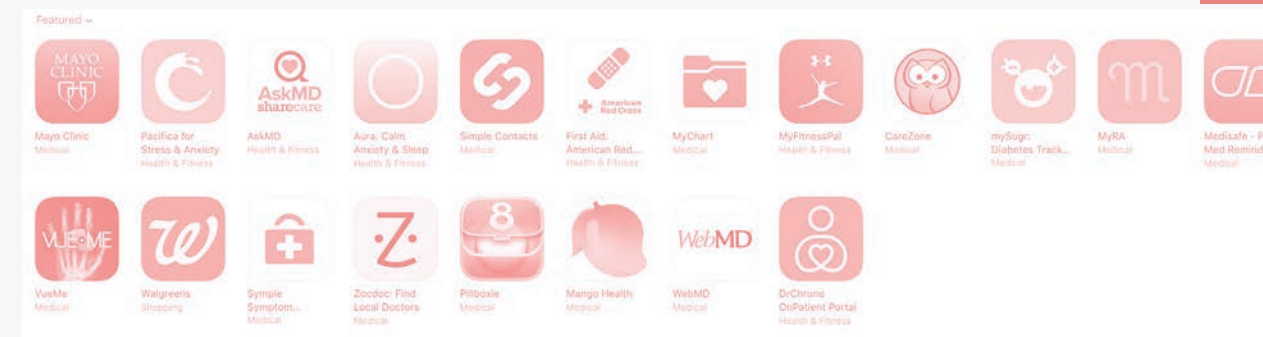
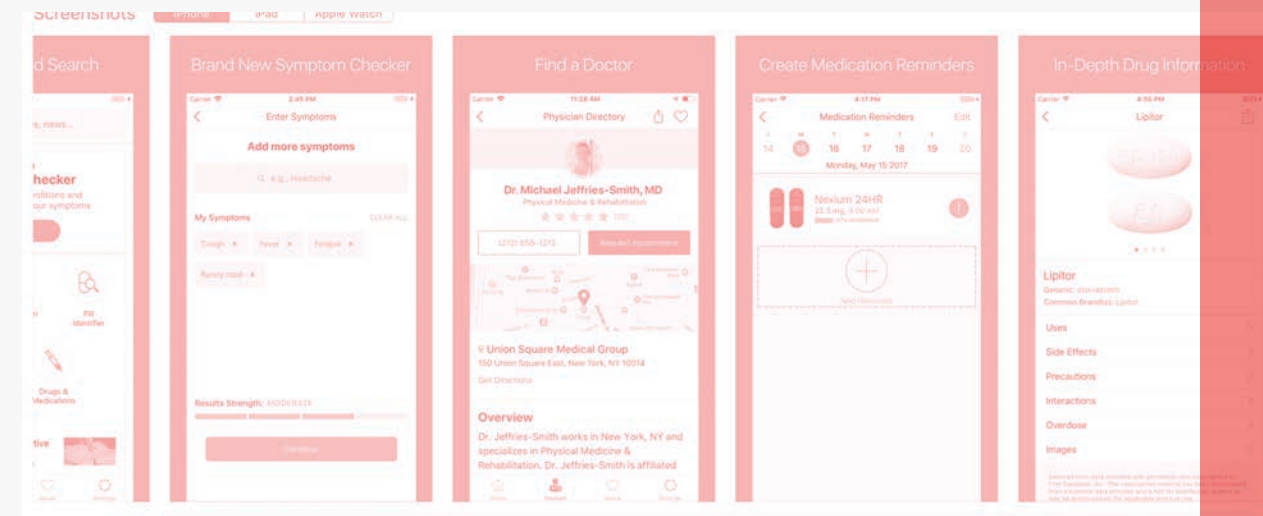
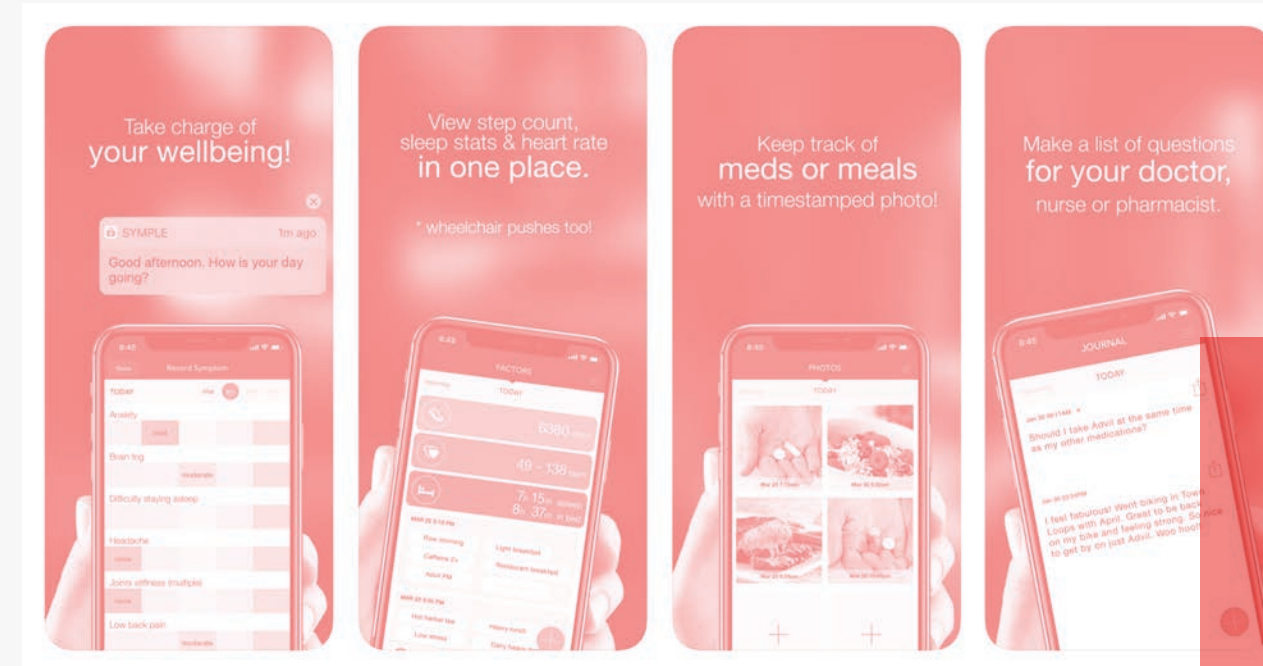
How do lay people determine what commercial interests lie behind the apps’ development & how might their data be used?

**1/3 of American smartphone users had used apps from the health and fitness category in January 2014.**

Lupton, “` It’s like Having a Physician in Your Pocket!’ A Critical Analysis of Self-Diagnosis Smartphone Apps.”

## Marketing Language

- “Symptom”
- “Diagnosis”
- “Medical” “Clinic”
- “Algorithms, Sensors, Software engineers, deductive logic, Artificial intelligence.”
- “Created by top Doctors”
- “Patent-pending”
- “Algorithmic”
- “Now ‘for the first time”
- “Doctors”
- “Medical Team”
- “Medication Reminder”
- “Drug info”



# Value Map

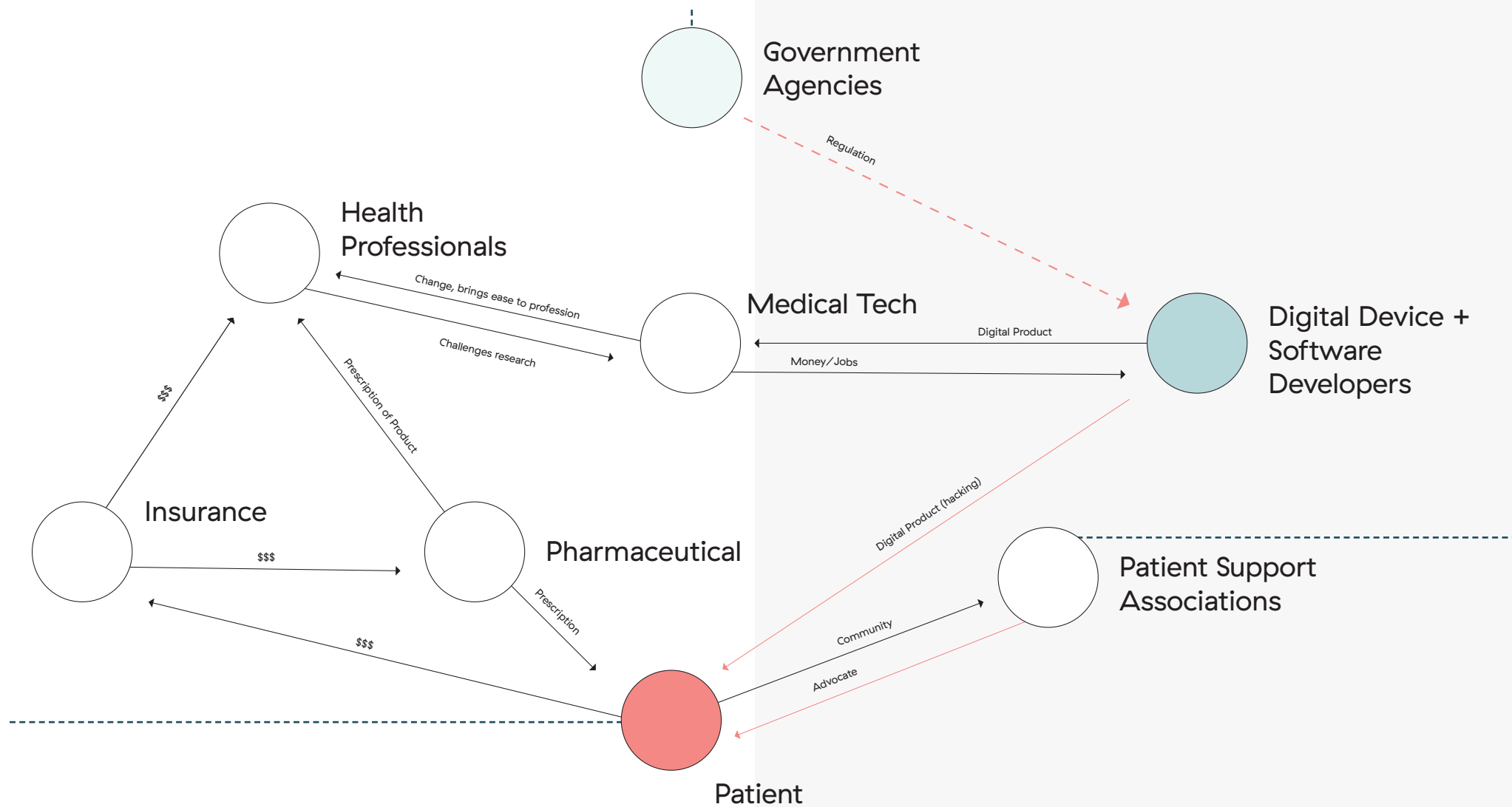
This map shows the value transfer of stake holders at large. How does medical Tech advance from the digital products created in the consumer market? The map shows different types of value, monetary, information, advocacy.

## Consumerist movement in healthcare 1970s

Since the 1970's Healthcare has shaped the focus to the patient encouraging them to become "Empowered & Engaged." The patient is supported in finding a self-management in their healthcare and is encouraged to challenge medical advice.

## GDPR

The General Data Protection Regulation shapes the way data is managed with the market. The law requires companies to have privacy processes in place that are easily accessed by the user. The policy hopes to ensure data rights protection.



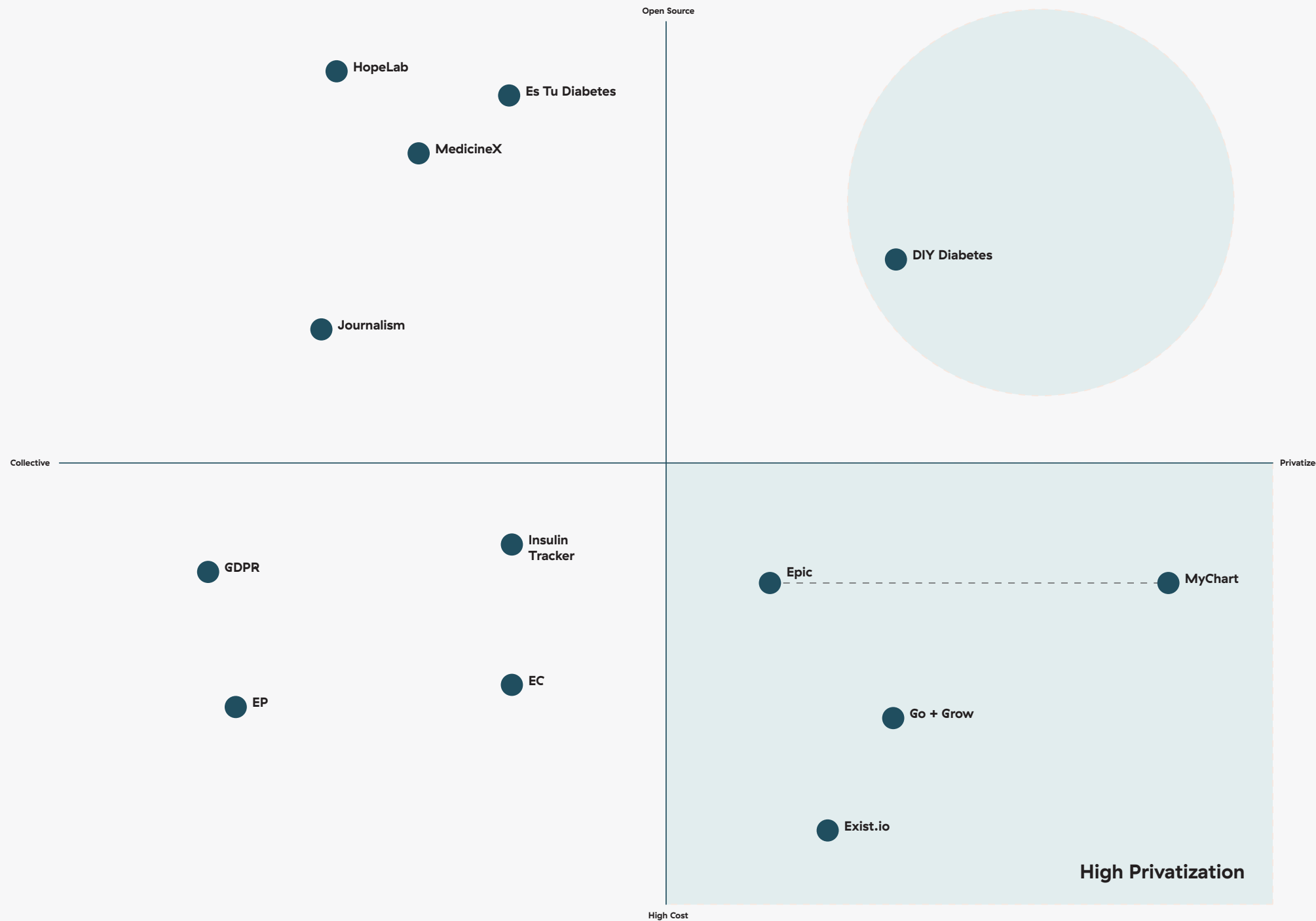
## Intervention Principle:

**Data Ownership should be transparent.** Clearly explain how the data will be used and collected

## Society for Participatory Medicine

The Society for Participatory Medicine is a support group for patient's interaction into the healthcare system. The group acts as a voice for the patient within regulation and policy changes.

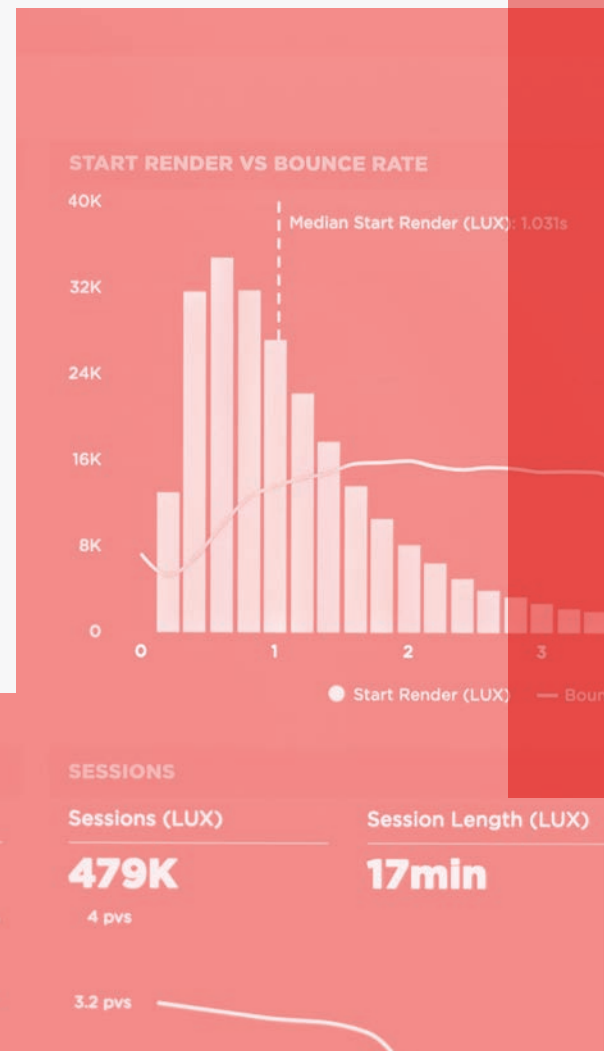
The society has more than 10,000 patients who agree to share their medical information publicly for research use.



# Opportunity: Patient Driven Solution

DIY Diabetes resides in an interesting place. The intervention utilizes open source programming and Private information to hack insulin readers to serve the purpose of the user. The users were upset with having to read insulin levels then administer the drug.

**The solution was discovered not by doctors or designers, but by the users** of the medication once they became more familiar with diabetic data and open source programming.





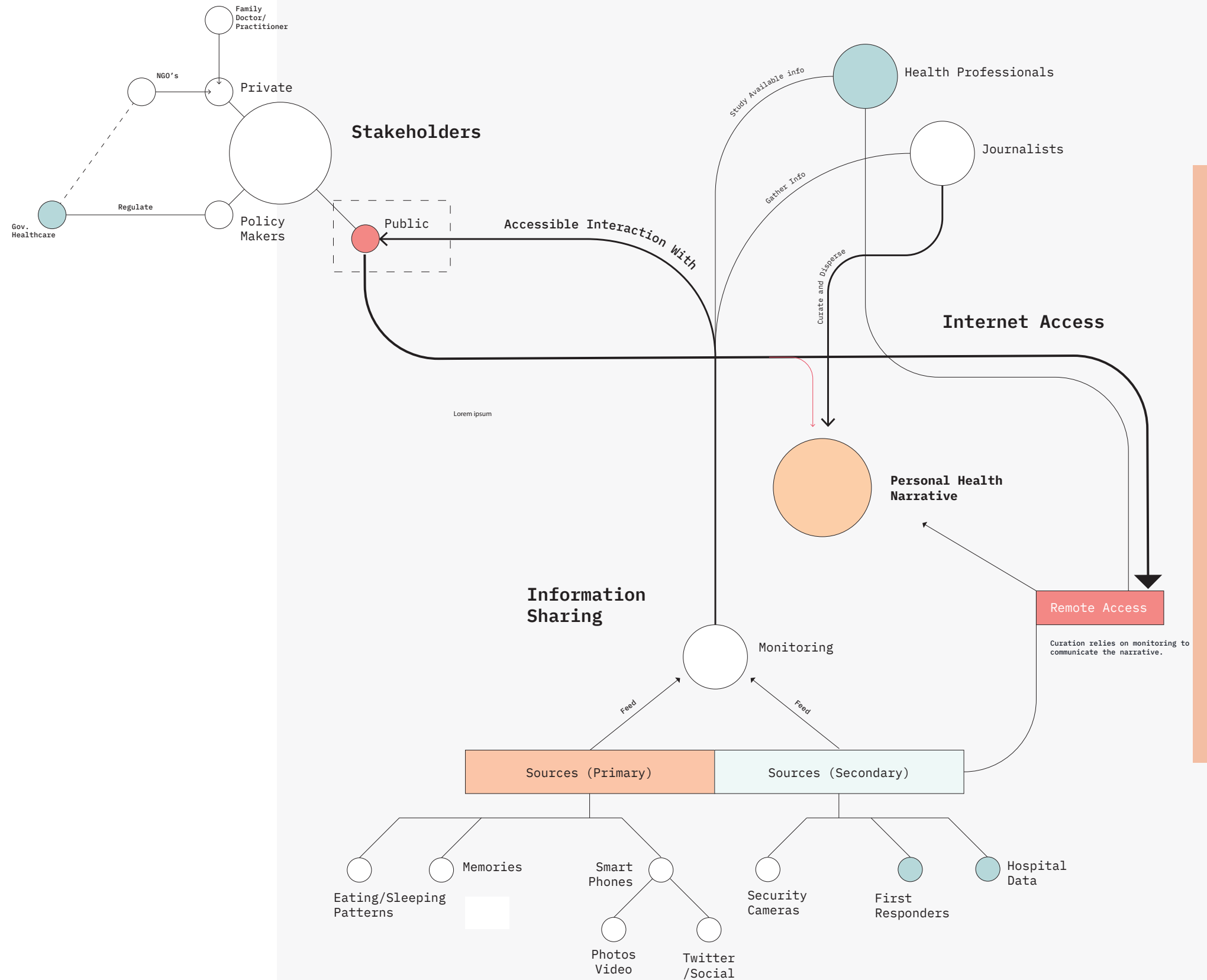
# Strategy

## Remote Access

Looking forward, it would be advantageous to see how data may be left in the hands of the individual, and how open-source technology may close gaps of health issues by eliminating restricted access. This section will illustrate some projections and models for design activity.

Digital Product comes with the advantage of remote access. An individual can use storage systems to archive important data and access instantly.

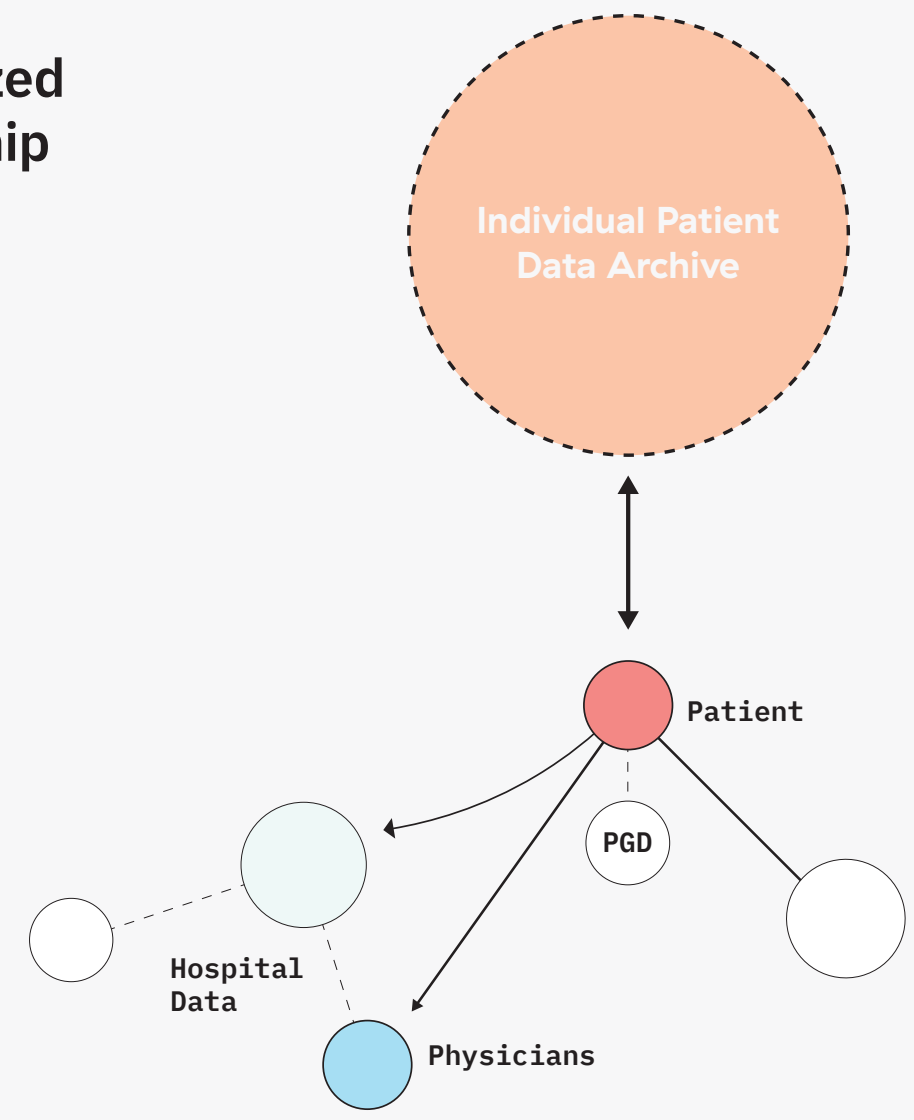
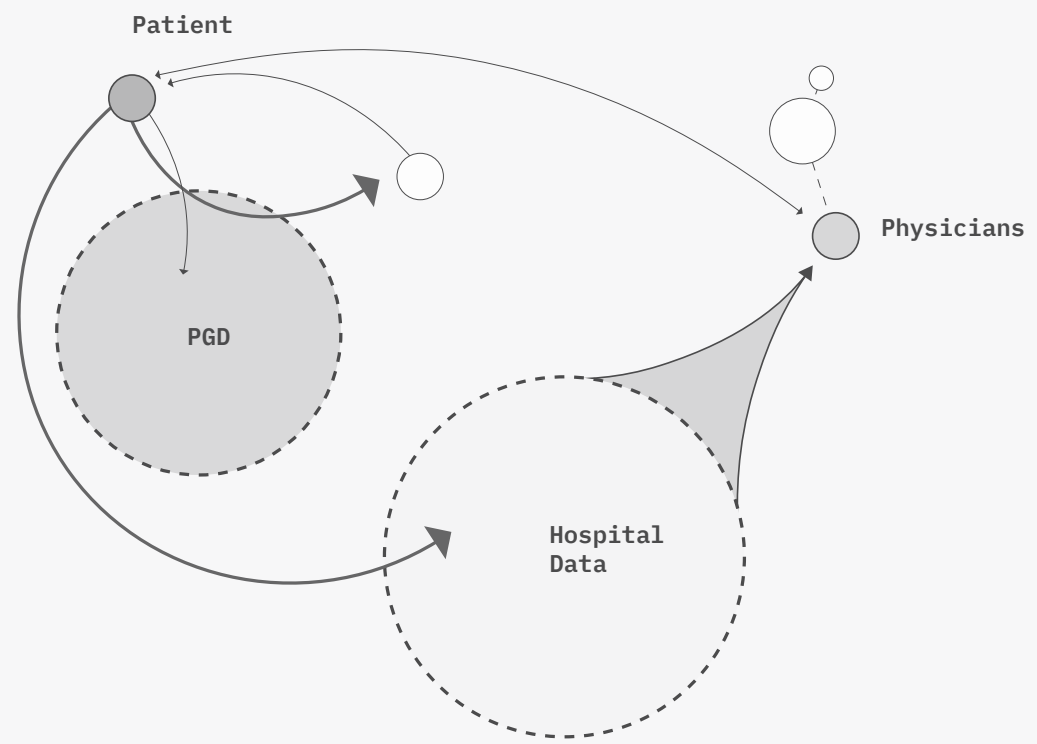
The diagram here shows one model of how the capture of data translates into a narrative with accessible literacy for the lay patient. By framing the insights as a **Personal Health Narrative** the individual is able to comprehend a personal story free of Medical Jargon.





From  
**Distributed  
Ownership**

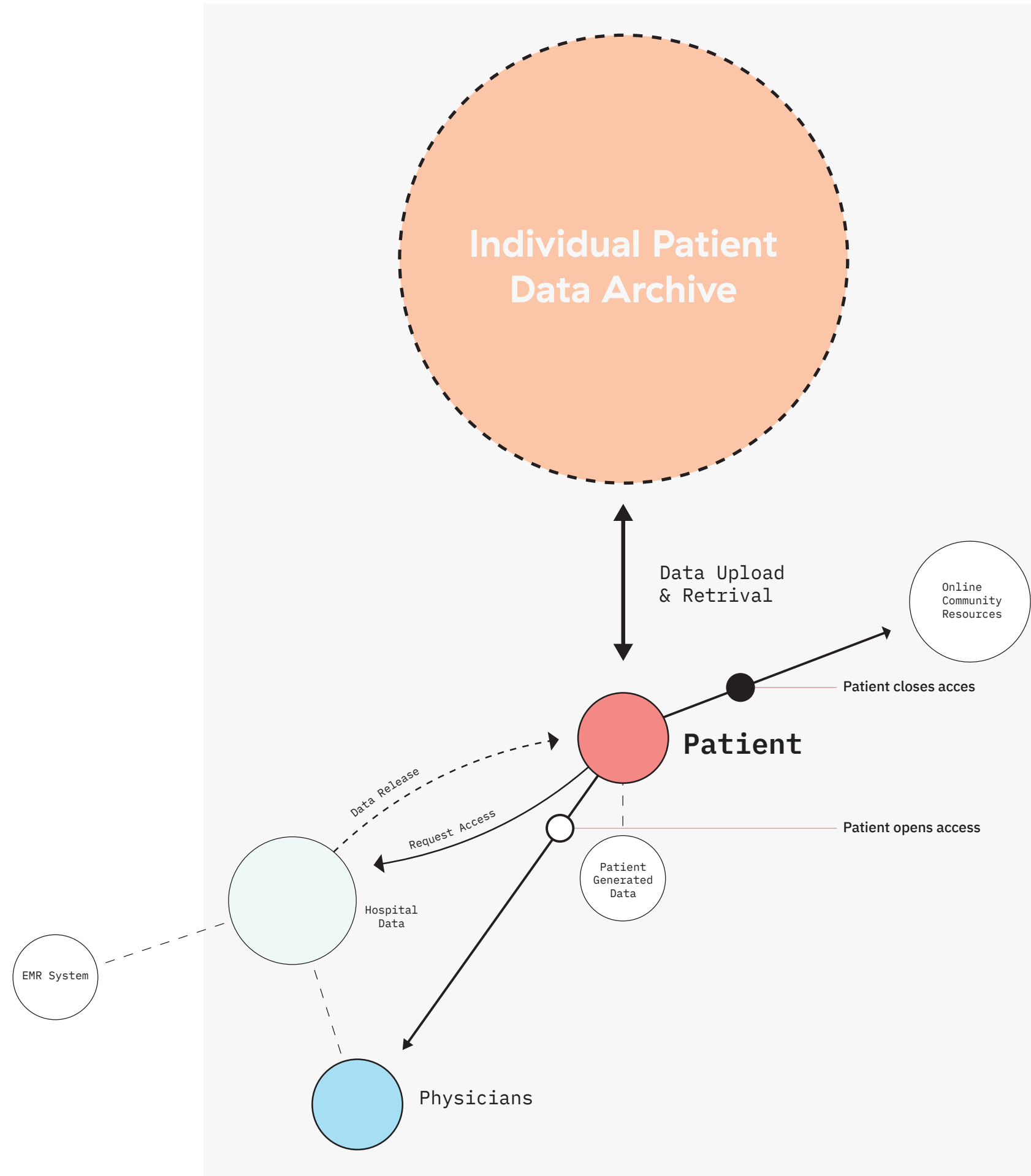
To  
**Centralized  
Ownership**



# Patient Releases Data

How might we position data in the hands of the individual? This **“future ecosystem”** puts the data in the hands of the individual by creating an archive that the patients pulls information from and shares it conditionally to whom they decide. The Patient can share with Online community or hospital records as they please.

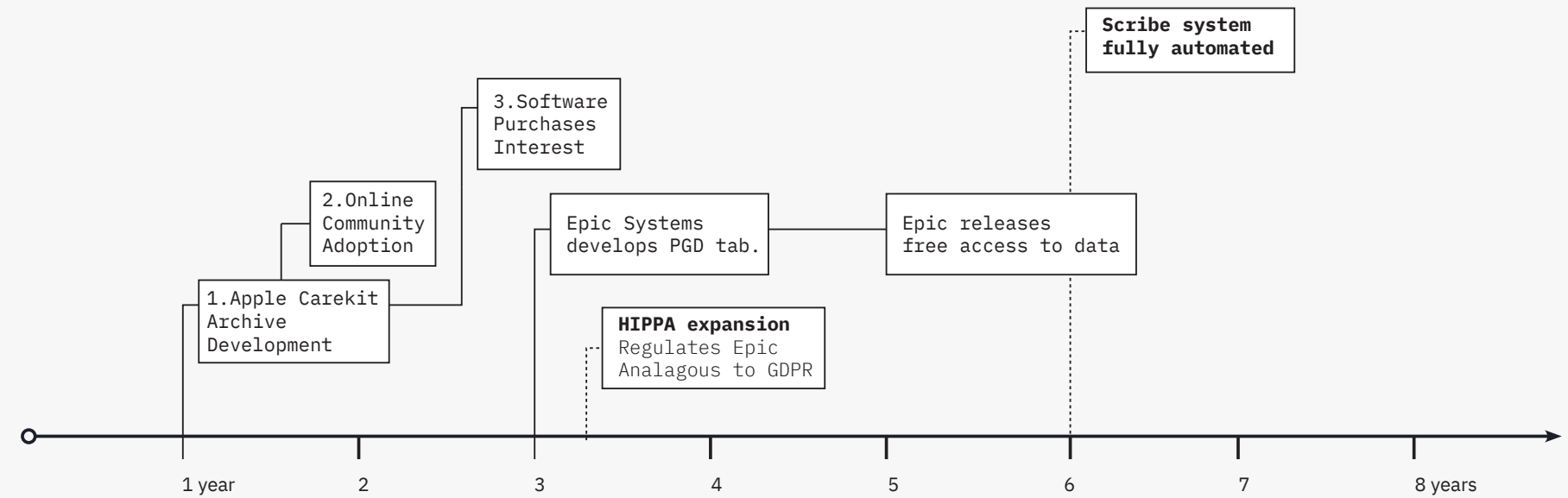
By **reversing ownership from the EMR companies to the individual**, the Patient becomes a more powerful stakeholder in the usage of their data.



# Next Steps

<b>BRIEF</b>	<b>Patient Generated Data Archive and Ownership</b>
<b>Project Description</b>	The patient's personal data is at the core of this project and how the usage+access of more detailed data can aid diagnosis through primary care.

## Implementation Timeline (Projection)





<b>BRIEF</b>	<b>Patient Generated Data Archive and Ownership</b>
<b>Project Description</b>	The patient's personal data is at the core of this project and how the usage+access of more detailed data can aid diagnosis through primary care.
<b>Objective</b>	<ul style="list-style-type: none"> <li>Use PGD to enhance primary care diagnosis. The utilization of Data sharing to increase patient empowerment and engagement with their own health data capture and record.</li> <li>Advocate for the access and individual patient ownership of data.</li> <li>Involve patient in the recording process of data between Medical Scribe and Physician.</li> </ul>

<b>Goal</b>	<ul style="list-style-type: none"> <li>Engage Patient in personal health data.</li> <li>Streamline/reduce burden of Data entry.</li> </ul>
<b>Target Audience</b>	<ol style="list-style-type: none"> <li>Patients with high technological capability and smart-phone use. Willing to freely give data to medical research.</li> <li>User of other smart-phone apps that include private data.</li> </ol>
<b>Points of Interaction</b>	<ul style="list-style-type: none"> <li>PGD includes easier opt-in from patient.</li> <li>Online open-source upload of PGD to archive and access.</li> <li>Interaction with personal archive. (capture)</li> <li><b>Over a two year time period:</b> Estimated HIPPA revisit after implementation.</li> </ul>

<b>Project Requirements</b>	<p><b>Constraints:</b></p> <ol style="list-style-type: none"> <li>EMR systems currently include fees for access to data by patient.</li> <li>There is too much data being forced in front of doctors. "Incomprehension Monster"</li> <li>HIPPA and GDPR restrict Medical Data access.</li> <li>Scribe network may decrease Market pressure for Improvement of EMR.</li> <li>EMR systems like Epic with 50% monopoly may react and combat with PGD functionality.</li> </ol>
<b>Design Principles</b>	<ol style="list-style-type: none"> <li>Secure and Private</li> <li>Open-source</li> <li>Highly-personalized.</li> <li>Consent</li> <li>Individual right to data access</li> </ol>



## Citations

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# Personal Reflection

Why don't I have access to my medical records? This is the question that brought me to the area of health data ownership and privacy. I recently established new care with a hospital and was surprised by how there was no accessible record of my past immunizations. In order to get access to them I was told it would take 24 hours and I must sign a release of information agreement. This was all quite the process for something I felt was a quite simple ask.

During the visit I brought up my concerns with my physician and explained the opportunity for a design project. Soon I had 3 doctors in the room asking me how we could do it (make epic more legible.) *While my blood was being drawn from arm.*

Through my research I have become aware of a few things that have shaped my view of design research.

## 1. Field of view.

Global Health is a Monster Problem. It is important to frame a section of it and focus on it while allowing in outside perspective. I found this through the Data privacy question in this project. Privacy is different for everyone and is expressed through different ways but it wasn't until I visited a physician myself that

I formed an opinion on how my data should be handled. Sometimes it just takes a phone call or a meeting with someone close to you to become more involved in the issue.

## 2. The Treasure Hunt (Mine field)

Because the topic of discovery was so big, I learned that an unwavering focus is a strong tool for tackling big issues. For every article you read, 10+ more questions can be asked to further your explorations. Those 10 questions lead you to 10 more readings, which lead to more questions. The cycle continues. It is with endless curiosity and gesture that I hope to find my solution.