

# The Internet of Me:

## Data Empowering Patients

Cardio Femme July 6th, 2018

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I could not figure out  
how to **take my pulse.**

**Exercise** >>>>

**1 sec**





270

*beats per minute*

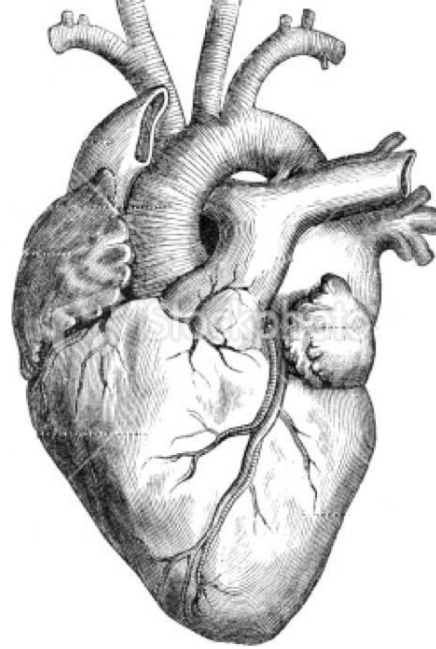


# *Maui, Hawaii*





atrioventricular node ablation  
*(electrocutation)*



# 100%

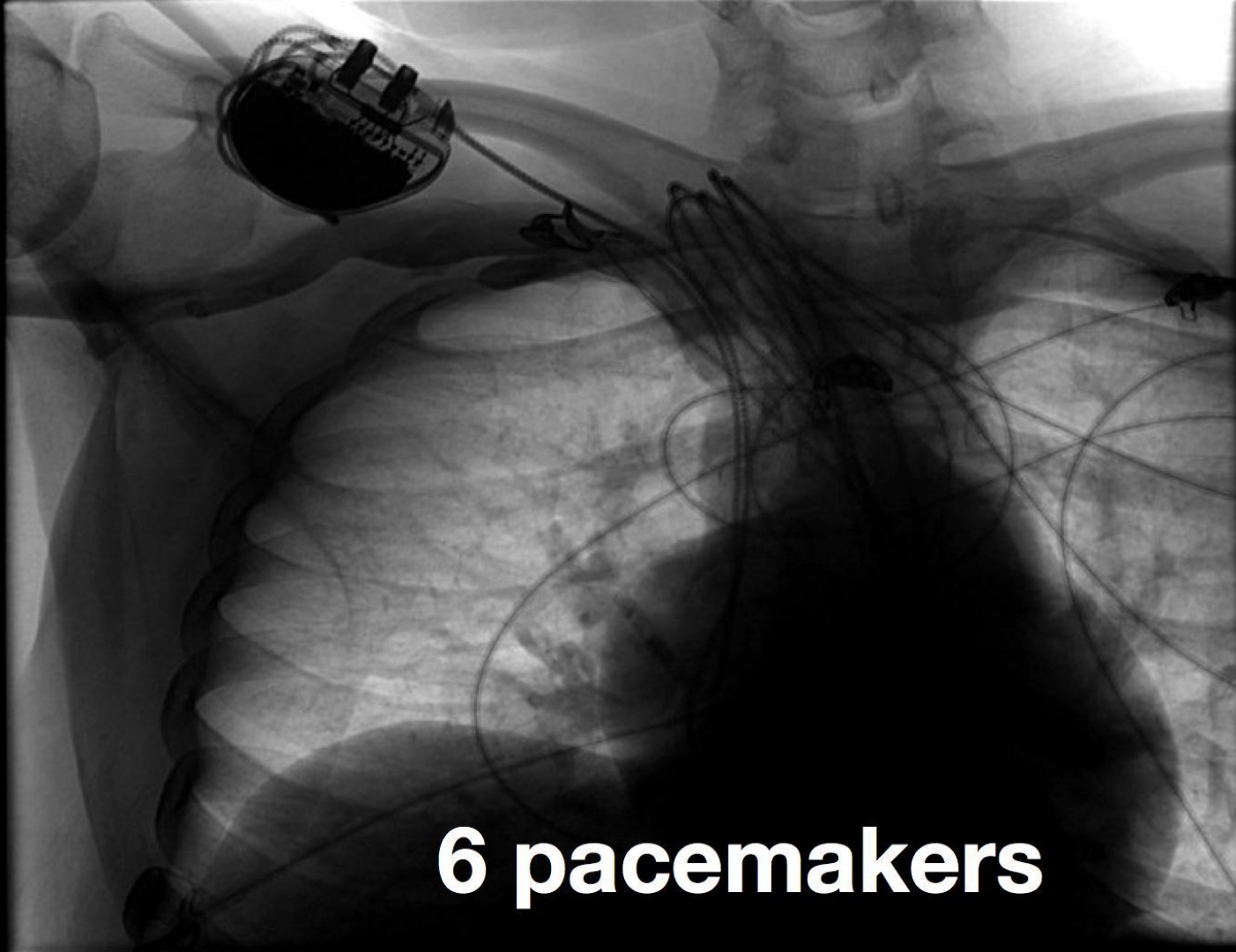
*battery dependent*



*How would I feel?*

*What would a pacemaker look like in my chest?*

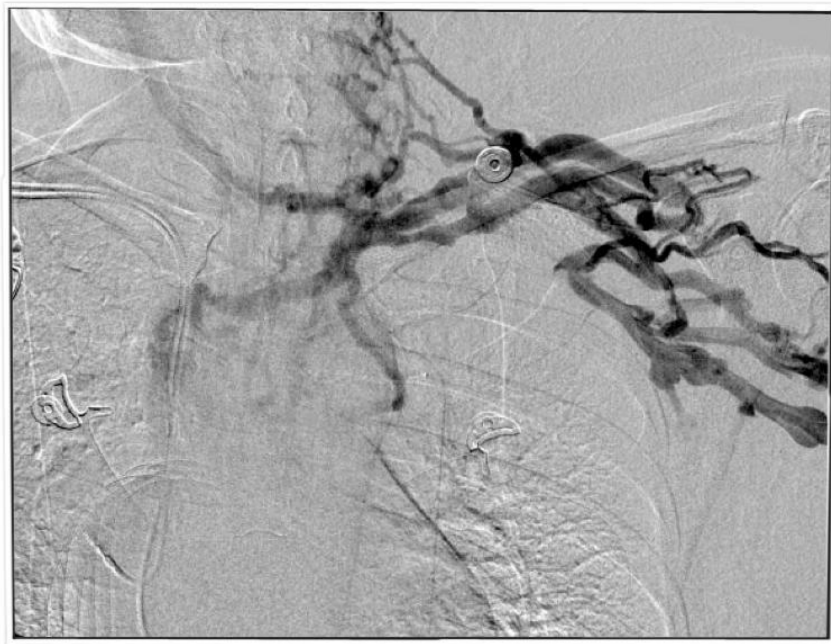
*Would I ever wear a swimsuit again?*



**6 pacemakers**



normal right side blood flow



blocked left side blood flow

*Am I really a **heart patient**?*

*How do I prepare for **open heart surgery**?*

*I need a goal: **LOTOJA Classic bike race**!*

*Glamour Shots*









*Everything was going so well...*



*leaking and bleeding internally*

*right lung collapsed*

*chest cavity filled up with blood*

*vital systems crashed*

*emergency bedside surgery*

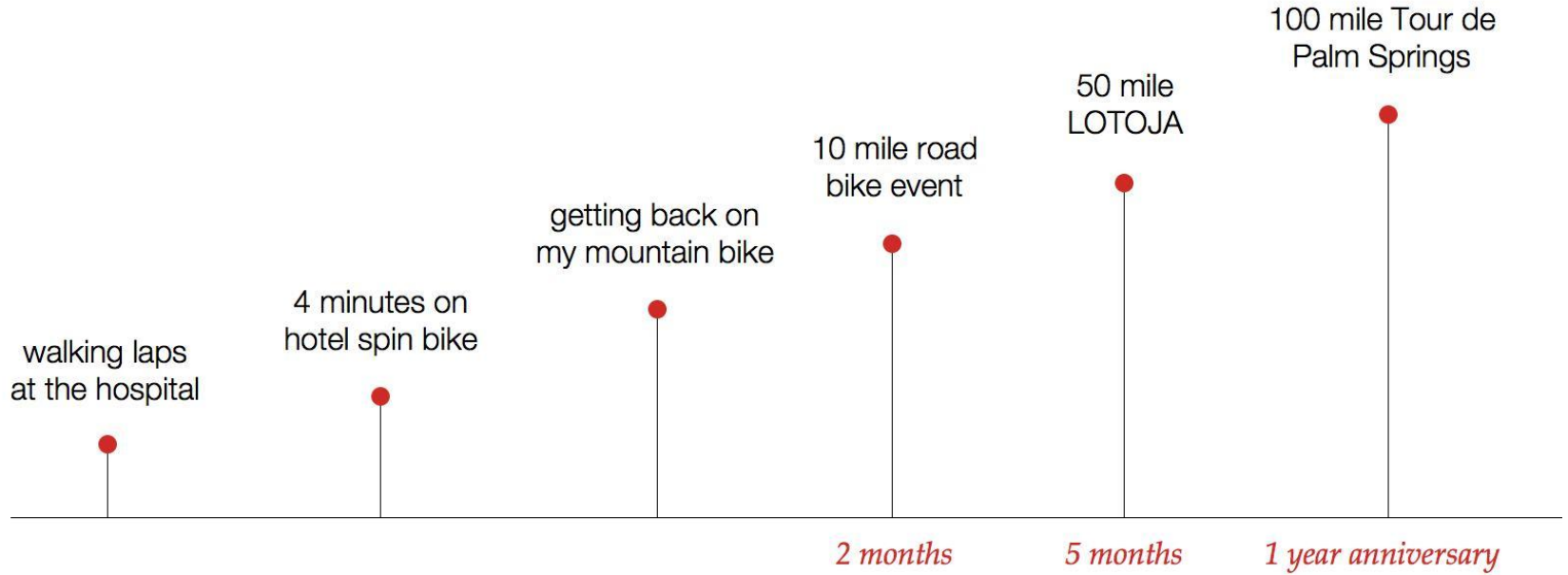
*blood transfusions*

*I might not live*

*back to ICU*

*lung surgery*





*post-surgery training plan*

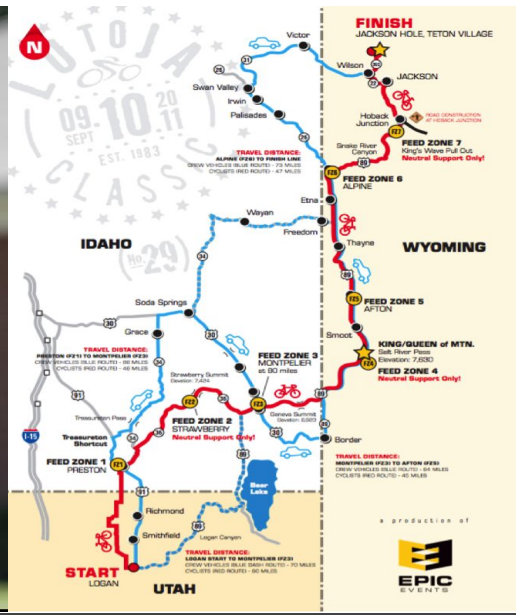


LOTTOJA  
1 DAY / 2 STATES / 206 MILES

1:51:41



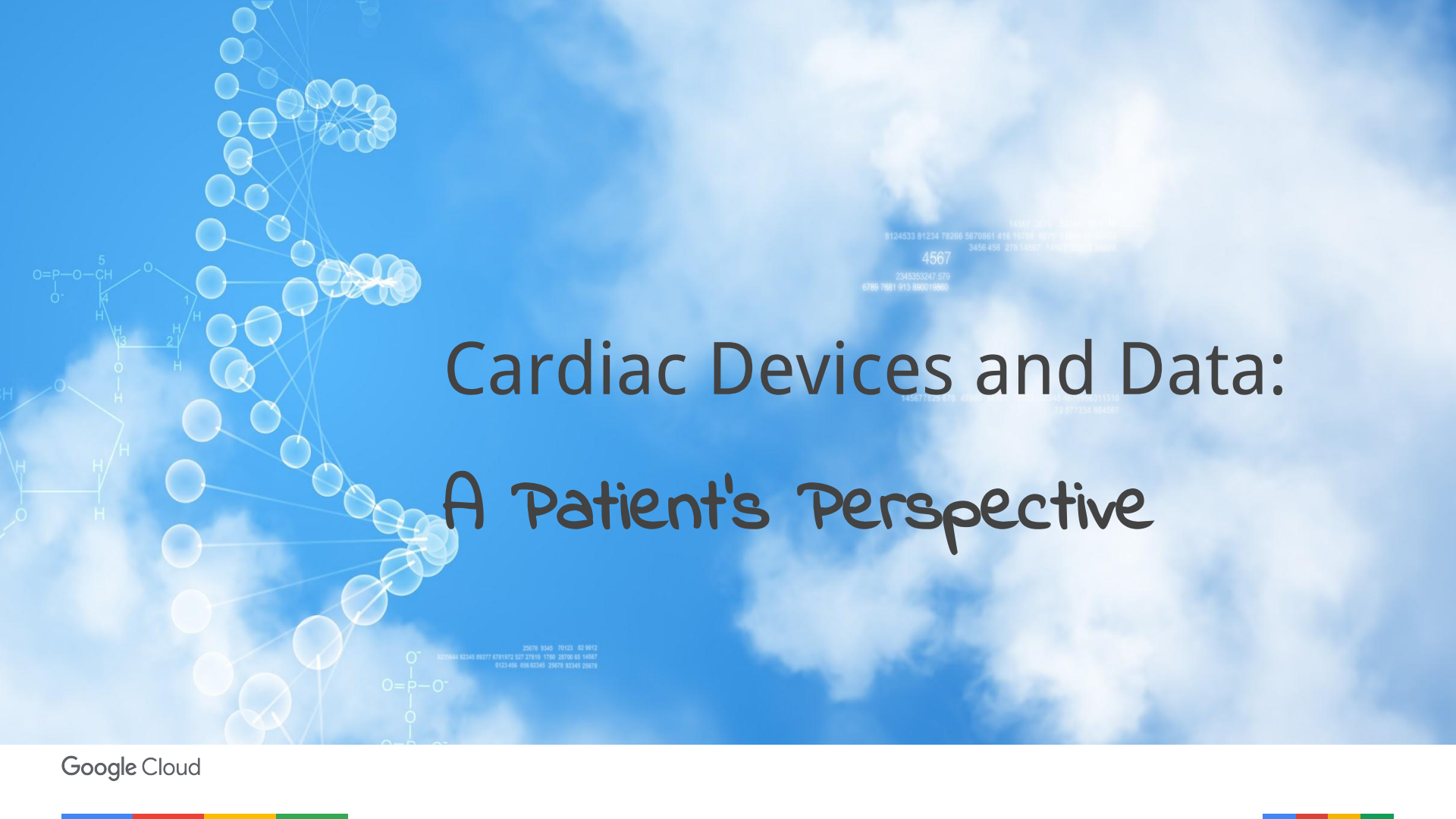




## Field testing:

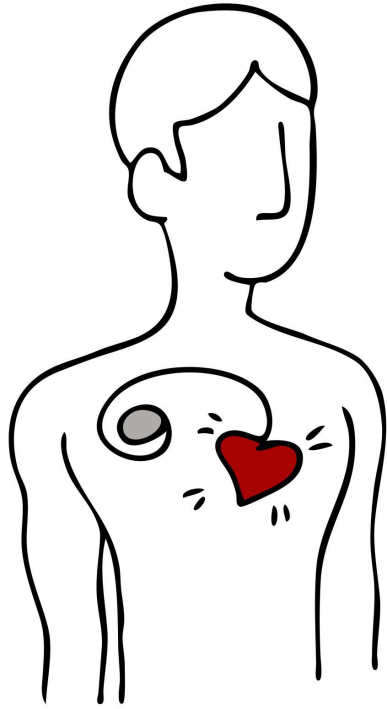
I refuse to sit still. Since having open heart and lung surgery in 2010, I've competed in multiple 200-mile, single-day road and gravel bike races around the world.

This has given me a unique experience as to how data collection, analysis and management can prove beneficial to personal health.



# Cardiac Devices and Data: A Patient's Perspective

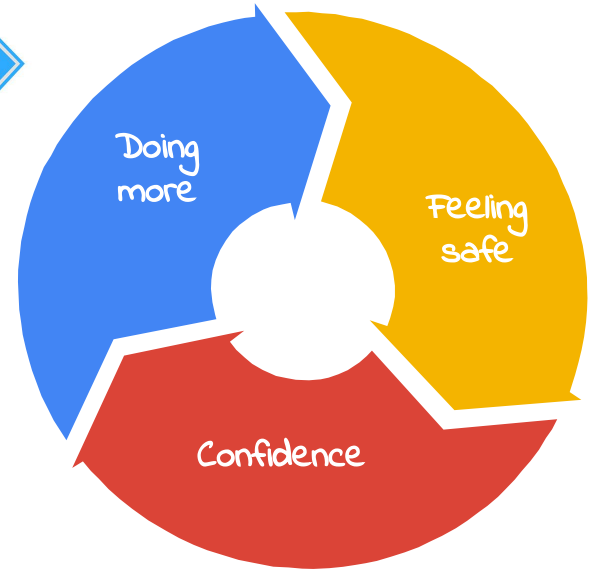




Is it working... Is it working... Is it working... Is it working?



overcoming the fear:




Help me feel safe!

# Data to live my life... and keep my Doctors in the Loop

- Devices offer a "window" into my body
- **Better discussions with my care team** It is not just about how "I feel" but having actual data points to support what is or is not going on!
- Not all successful **"healthcare"** comes from the clinic:
- Peer-to-peer support and sharing of information. No one understands like someone that has been there via **online support communities.**



# Data from my Pacemaker:

LATITUDE® Patient Management - Combined Follow-up Report		Report Created: Jun 22, 2016
	Dohse, Heidi (01126890)	
	Date of Birth: Jan 23, 1964	Latest Device Transmission: Apr 11, 2016 13:38 EDT
	Device: ADVANTIO K063J121439	Last Office Interrogation: Apr 06, 2016
	Clinic: UCSF EP & Device Clinic	Implant Date: Jan 31, 2013
	Search Tags: PACER	Patient Group: All patients (Primary)

## My Alerts

There are no alerts to display.

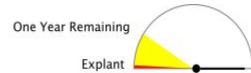
## Events Since Last Reset (Apr 06, 2016)

Apr 10, 2016 23:48 RV Auto

## Battery OK

Approximate time to explant: 6 years from Apr 11, 2016

Magnet Rate 100 ppm



See last page for additional battery information.

Leads	Implant (Jan 31, 2013)	Most Recent In-Office Measurement (Apr 06, 2016)	Most Recent Daily Measurement (Apr 10, 2016)
<span style="color: blue;">●</span> Atrial			
Intrinsic Amplitude	2.0 mV	1.8 mV	1.7 mV
Pace Impedance	650 Ω	832 Ω	794 Ω
Pace Threshold	0.6 V @ 0.4 ms	0.7 V @ 0.4 ms	
<span style="color: purple;">■</span> Ventricular			
Intrinsic Amplitude	N/R	N/R	N/R
Pace Impedance	500 Ω	534 Ω	508 Ω
Pace Threshold	0.7 V @ 0.4 ms	Auto 0.8 V @ 0.4 ms	0.8 V @ 0.4 ms

## Settings

### Ventricular Tachy

Ventricular Tachy EGM Storage On  
 Detection Rate 190 bpm (316 ms)

### Atrial Tachy

ATR Mode Switch 190 bpm DDIR ● Atrial 2.5 V @ 0.4 ms  
 Brady Auto 1.3 V @ 0.4 ms

### Mode

Mode DDD ■ Ventricular Sensitivity

Lower Rate Limit 50 ppm ● Atrial Fixed 0.5 mV

Maximum Tracking Rate 185 ppm ■ Ventricular Fixed 2.5 mV

Maximum Sensor Rate 185 ppm

Paced AV Delay 100 - 150 ms

Sensed AV Delay 85 - 130 ms

A-Refractory (PVARP) 200 - 200 ms

V-Refractory (VRP) 160 - 250 ms ● Atrial Bipolar

### Pacing Output

● Atrial 2.5 V @ 0.4 ms  
■ Ventricular Auto 1.3 V @ 0.4 ms

### Sensitivity

● Atrial Fixed 0.5 mV  
■ Ventricular Fixed 2.5 mV

### Leads Configuration (Pace/Sense)

● Atrial Bipolar  
■ Ventricular Bipolar

### Rate Adaptive Pacing

Minute Ventilation ATR Only  
 Accelerometer ATR Only

## Trend Graphs

Most Recent Measurement: Apr 11, 2016





VARIANTS

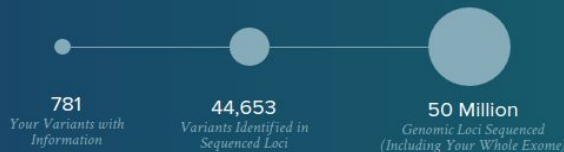
781

[View variants](#)

*Your Variants with Information*

This tool enables you to learn more about genomics by exploring your variants that have information.

[Genetics 101 >](#)



CONDITIONS



*View conditions associated with your variants with information*

TRAITS



*Learn how the variants found in your genome influence your traits.*

VARIANTS



*Explore the list of your variants that have information.*

MAP OF CHROMOSOMES You have 781 variants with information in your genome. Choose a chromosome to zoom in.



Disclaimer: This tool enables users to explore their genomic variants identified by comparing their DNA sequence to a standard reference genome maintained by the Genome Reference Consortium (GRC). The information that can be accessed through this tool does not provide a diagnosis, prediction, prognosis or other medical advice of any kind.

[View Variants Report](#)

## Genomic Data:

- Link to heart issues?
- Donate to research

# genome variant Details:

There are 536 conditions in **NHGRI CGD** associated with genes where you have variants with Information.



**CARDIOVASCULAR** ✕

You have 176 conditions with findings in this category.



Remember, you may see variants that have been associated with medical conditions in the scientific literature. That doesn't mean you have those conditions. Genos is not intended for diagnostic or prognostic use. If you have any health-related questions about your DNA sequence information, contact your doctor.

Condition Name ▾

Search ✕ ☰ ☱

Condition	Variants	Assessments
<b>Acrodysostosis 1, with or without hormone resistance</b> <i>Cardiovascular, Dermatologic, Endocrine, Musculoskeletal, Neurologic, Oncologic</i>	1	1
<b>Acute myeloid leukemia, familial</b> <i>Oncologic, Allergy/Immunology/Infectious, Cardiovascular, Audiologic/Otolaryngologic, Dermatologic, Hematologic, Pulmonary</i>	1	1
<b>Acyl-CoA dehydrogenase, very long chain, deficiency of</b>	1	1



# Mobile Data and Social Sharing:

The Fitbit mobile app dashboard displays various health and activity metrics. At the top, it shows the time (7:11 PM) and battery level (60%). The main section features four large green icons representing floors (13), miles (8.88), calories (3,662), and minutes (127). Below this, there's a section for social inspiration: "Stay inspired by adding friends or joining groups." The dashboard is divided into four quadrants: "1 of 5 Days weekly exercise" with a runner icon, "7 hr 23 min 1 hr 4 min awake" with a moon icon, "61 resting bpm" with a heart icon, and "Female Health Tracking and Trends" with a plus sign icon. The bottom navigation bar includes Dashboard, Challenges, Guidance, Community, and Notifications.

The Blaine County Mountain Biking activity screen shows a heart rate graph and training effect data. The top bar indicates the time (8:51 AM) and battery level (99%). The main section displays "Heart Rate (bpm)" with an average of 140 and a maximum of 162. Below this is a red heart rate graph showing fluctuations over time, with markers at 0:13:14, 0:27:20, 0:41:25, and 0:55:31. The "Training Effect" section shows two circular gauges: "0.8 Anaerobic" and "3.1 Aerobic". The "Elevation (ft)" section shows a minimum of 5,485 and a maximum of 6,148. The bottom navigation bar includes icons for a folder, document, refresh, and line graph.

The Ride feed screen displays a summary of a ride and social sharing options. The top bar shows the time (8:54 AM) and battery level (98%). The main section features a "Feed" header with "Ride" and "Edit" options. Below this, there are social sharing icons: a thumbs up (22), a comment (0), and a share icon. The ride summary includes "25.1 mi DISTANCE", "1:35:51 TIME", "525 ELEV GAIN", and "629 CALORIES". A trophy icon indicates "x 8" achievements. Below the summary, there's a section for social interaction: "With someone who didn't record?" and an "Add Friend" button. The "Purple Bike" is listed as the ride name. The "RELATIVE EFFORT" section shows a score of "132" with the text "Nicely done. This was a stronger effort than usual." Below this, there are three horizontal bars: "Higher than average" (red), "Your 3-week average" (purple), and "Lower than average" (blue). The bottom navigation bar includes Feed (with a 30 notification), Explore, Record, Profile, and More.

**HIPAA AUTHORIZATION FORM B**  
(This brings in your medical records from other doctors, therapists, hospitals, etc.)

Printed Name: \_\_\_\_\_

I, hereby authorize (insert name of practice / person)

\_\_\_\_\_  
Phone# \_\_\_\_\_ Fax# \_\_\_\_\_

to release the following information: (Please be specific and check those that apply)

History & Physical	Activity / Occupational Assessment
Psychiatric Assessment	Clinical & Laboratory Results
Psychological Evaluation	Pregnancy Status
Treatment Plan / Report	Discharge summary from @ facility/practice
Vocational Assessment	Transfer Forms
Physician Progress Notes	Radiology Films or Disk and Reports

To: Jonathan Woodcock, MD, Neurological Rehabilitation Resources, PC  
C/O: Sara Burns, 8515 Pearl Street, #203, Thornton, CO 8022, Fax: 303-288-7874 / Email: [info@nrmd.com](mailto:info@nrmd.com)

Neurological Rehabilitation Resources does not pay for copying or mailing fees. These fees are the responsibility of the patient or the authorized personal representative. **(Please do not fax over 25 pages)**

**This Private Health Information (PHI) is being used or disclosed for carrying out treatment, evaluation, disability evaluation, payment and/or:** \_\_\_\_\_  
(HIPAA requires you to provide a specific reason(s))

This authorization shall be in force and effect until (specify date) \_\_\_\_\_ or (specify an event that relates to the patient or the purpose of the use or disclosure) \_\_\_\_\_ at which time this authorization is to be used and the disclosures expiration. I understand that I have the right to revoke this authorization, in writing, at any time by sending a revocation.

I understand that the information used or disclosed pursuant to this authorization may be subject to re-disclosure by the recipient and may no longer be protected by federal or state law. I understand that I have the right to inspect or copy the PHI to be used or disclosed as permitted under federal or state law. I understand that I have the right to refuse to sign this authorization.

Patient's Social Security # \_\_\_\_\_ Patient's Date of Birth \_\_\_\_\_

Signature of Patient or Personal Representative: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Patient or Personal Representative: \_\_\_\_\_

Description of Personal Representatives Authority: \_\_\_\_\_

**This form may be photocopied.**  
**Each entity/person releasing your medical records needs a separate form.**



Everytime we go to the doctor in the United States we are handed the HIPAA consent form. We are conditioned to think that horrible things will happen should anyone even glance at our medical data.

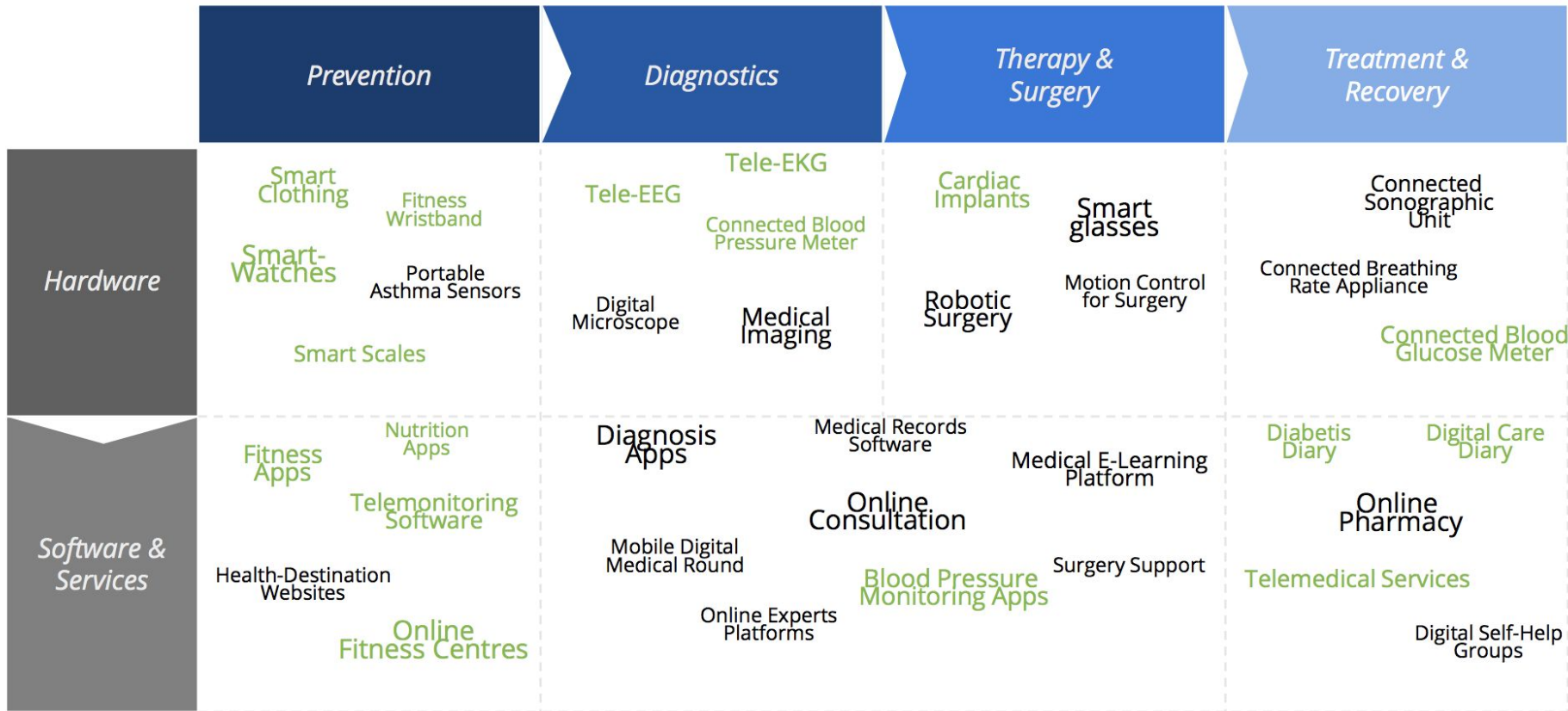


When the quality and length of your life is dependant on the medical world making advances, you don't mind sharing your data.

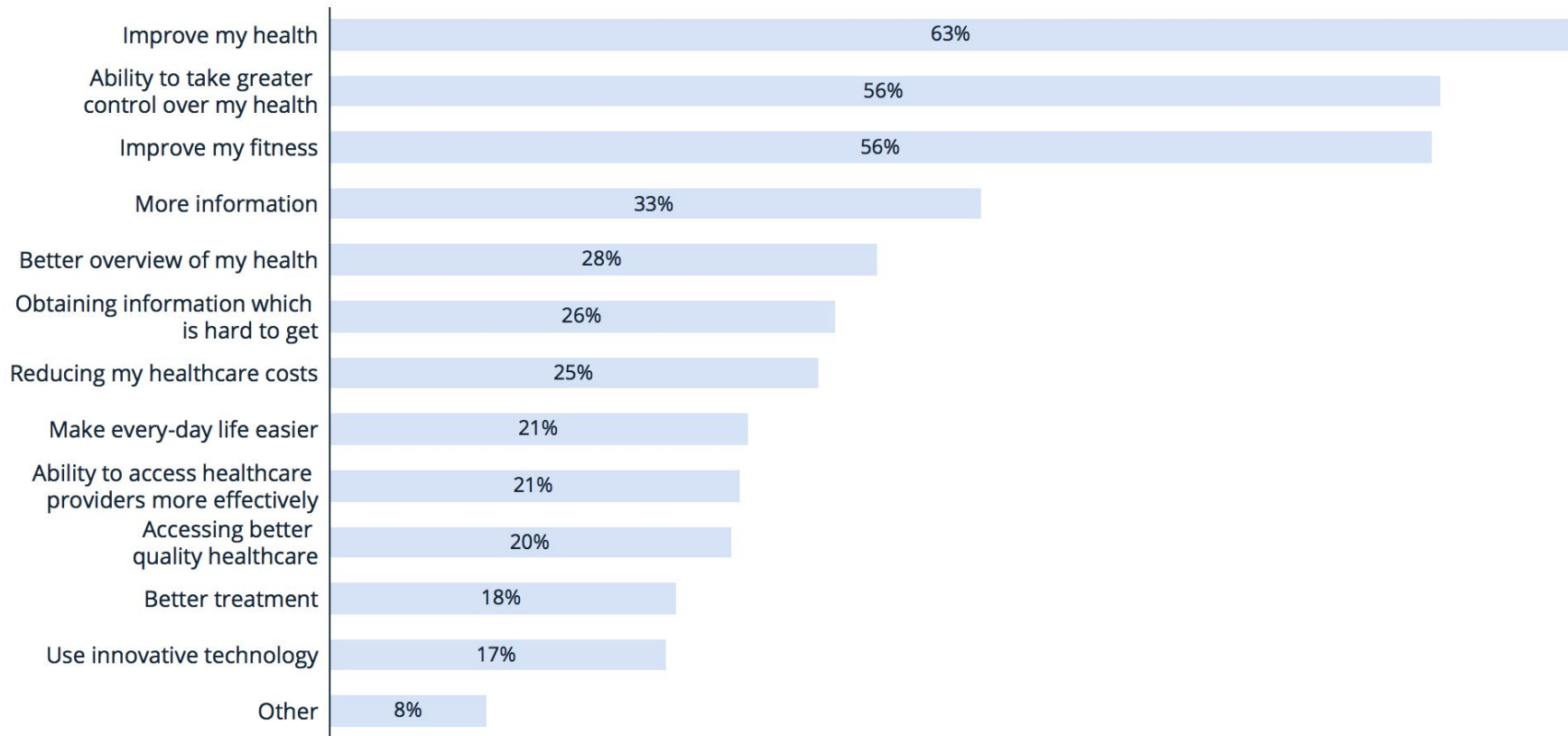
Personally, I just want to control who is using it and for what. I want to give the consent and be valued for my contribution.



# Healthcare IT Scenarios:



# eHealth User Adoption Potential:



# Patients as Mentors:

 **Whitney Zweifel**  
July 2 at 4:12 PM

I just need to vent to people who will understand. I'm so fed up with my heart. I hate summertime, it's so dang hot and humid here. It makes it hard to breathe and I'm always drenched in sweat. I'm so tired of being a sweaty, hot, slob (my opinion because I literally never feel clean - it's so humid you walk outside and are drenched from the air). My BP was up at my appt and has been crazy labile lately - 135/90 and I take 150 mg of metoprolol Er. I don't want to increase the dose again because I've gained so much weight already. Ugh....it just never ends. 😞

Like Comment

 **Cherise Peterson**  
June 25 at 12:52 PM

So trying to figure out if anyone has something like this happen before. I'm having random pains center of my chest. Feels like I'm being shocked. Randomly comes and goes. Never can pinpoint what triggers it. I have put a call into my cardiologist but waiting for callback. Just seeing if anyone has experienced this.


Like Comment

1 Seen by 86

 **Lori Adkins** Obviously I would get that checked out, but I know a lot of people complain of that symptom and it seems to be nerve-related.

Like · Reply · 1w · Edited

 Cherise Peterson replied · 8 Replies


 **Lori Adkins**  
July 1 at 4:47 PM

What's up, people? Anybody else's pacer get wonky in the heat? Talk to me....


Like Comment

1 Seen by 97


View 7 more comments

 **Erin Alex Steverson** I'm ready to move up north it's to dam hot here . 125 was the high today ..

Like · Reply · 3d

 **Valerie Plant** No, but the heat alone can increase your heart rate alone.

Like · Reply · 1d · Edited

 Valerie Plant replied · 2 Replies

Write a comment...

 **Mike Nail** shared a link to the group: Paced (as in Pacemaker enhanced) Athletes.  
July 1 at 6:01 PM · 📷

<http://chat.clevelandclinic.org/chatpage.aspx?chatid=16027>

Here's a web chat hosted by Cleveland Clinic, specifically addressing sports cardiology. If you want to get a question answered about a particular issue, register and send the question in before the chat date. I think they take them first come first served. If you can't listen live, they publish transcripts after the event.

 CHAT.CLEVELANDCLINIC.ORG  
**Cleveland Clinic: Health Chats**  
Get answers to your health questions and concerns. It's easy to be part of our live chat events, led by Cleveland Clinic physicians and health professionals.

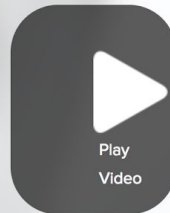
4 Like Comment

# Opportunities to Donate Data for Research:

[Home](#)[Study](#)[Community](#)[Team](#)[FAQs](#)[Login](#)

## Join the study to end heart disease.

Be a part of an ambitious study to end heart disease. It only takes a few minutes to make a big difference. Anyone can join — whether you have heart disease or not.



[Join the Study](#)

Brought to you by



UCSF

in collaboration with



American Heart Association

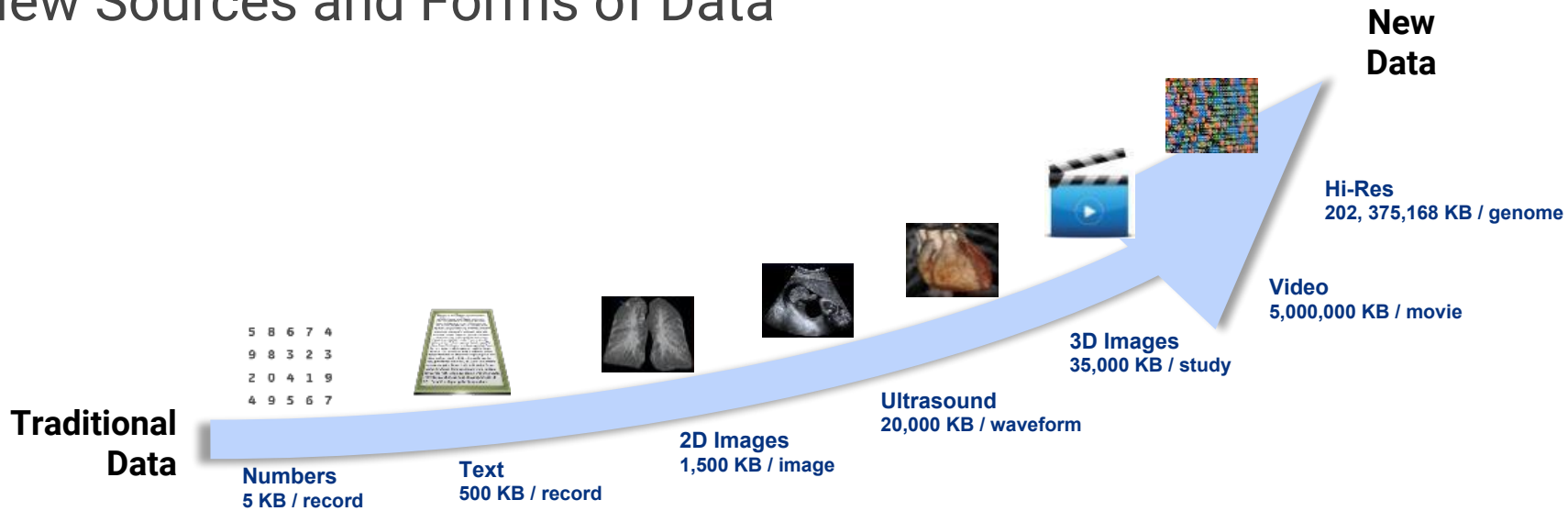
Life is Why™

# Accelerating Delivery of Healthcare Solutions on Google Cloud





# New Sources and Forms of Data



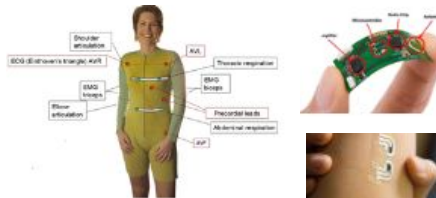
## Mobile Devices



## Registries / Exchanges



## Wearable Sensors



## Activity Tracking



## Bio Diagnostics



# Obstacles to unlocking healthcare data...

Healthcare data is stored in disparate systems and formats

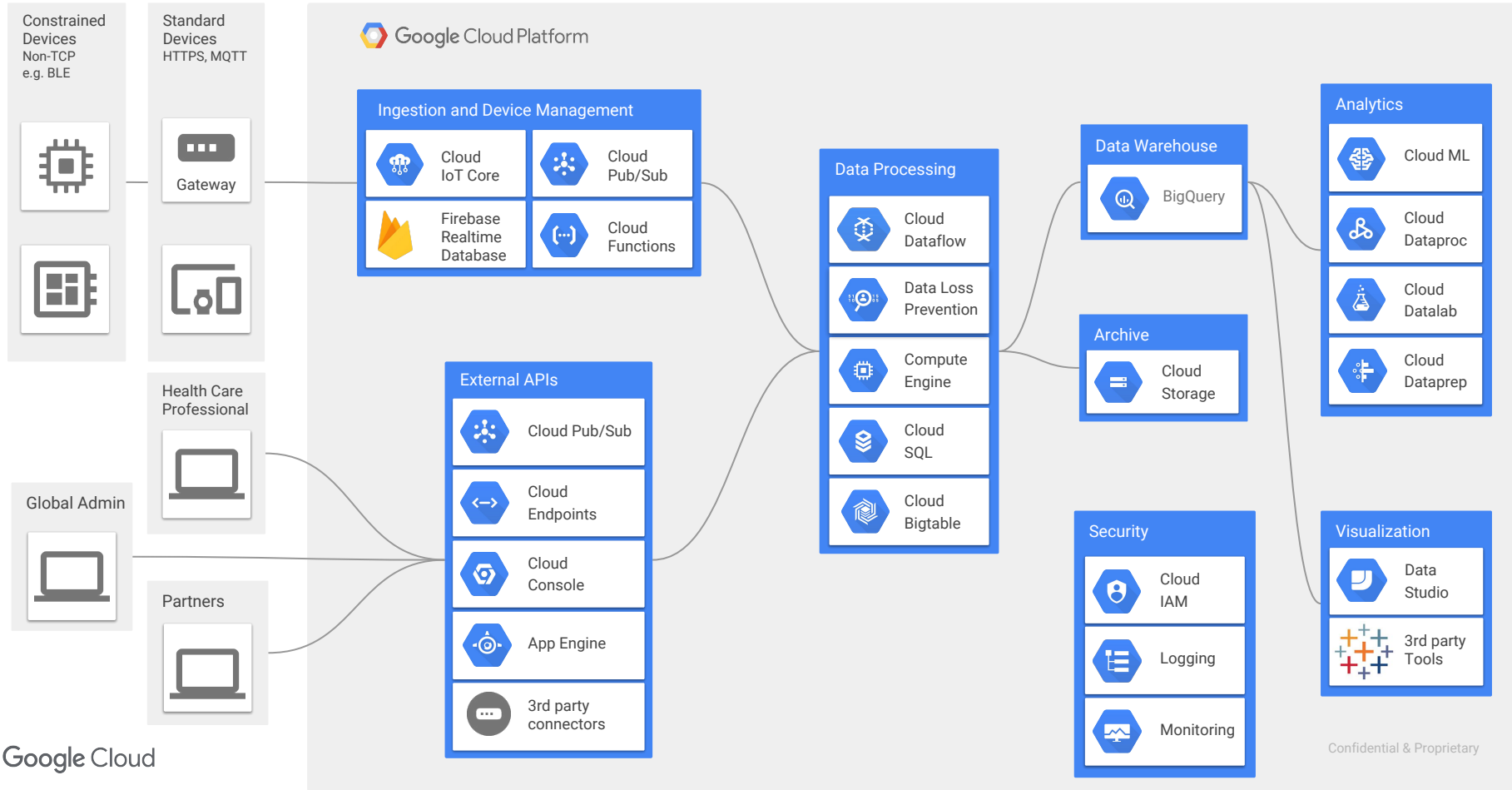
Data often exists as “unstructured notes” or images of faxes

Data must be “de-identified” in order to share or aggregate for training models

Privacy agreements and patient consents block many data use cases

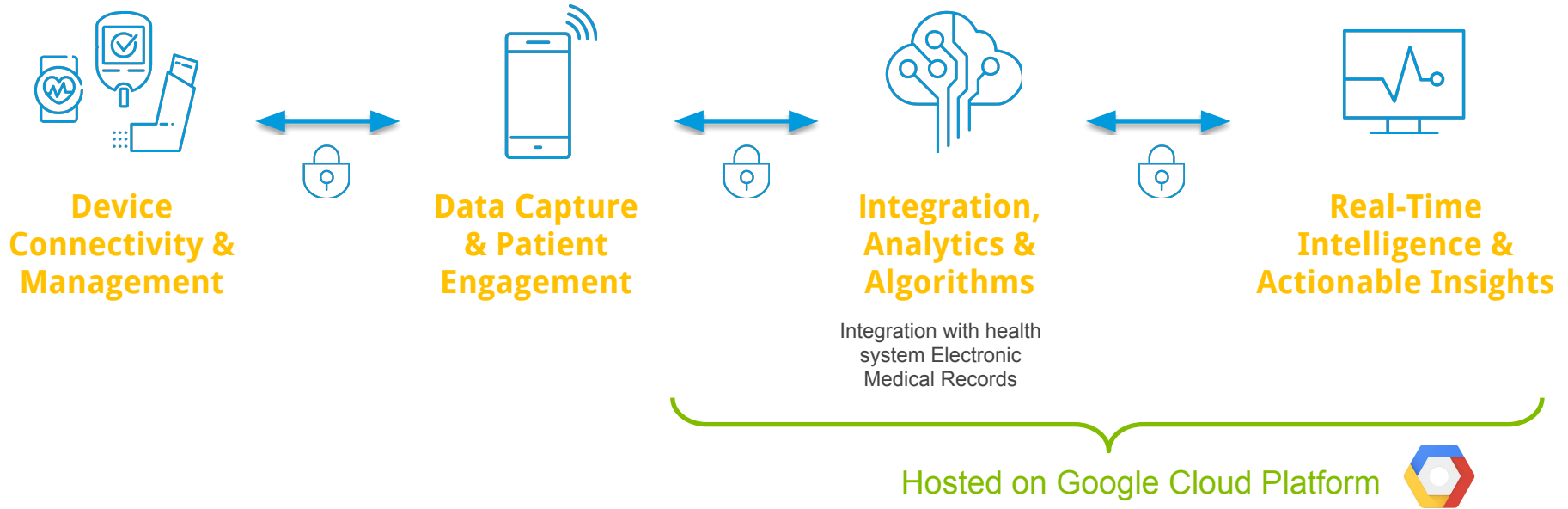
Medical diagnoses are subjective so quality labels for ML are scarce

# Cloud IoT Core for Mobile Health Data



# Flex Digital Health - BrightInsight

Managed services platform supporting Class I, II, III medical devices, combination products and Software as a Managed Device (SaMD)



# Final Thoughts...

As a lifelong heart patient, I have waited a long time for all the pieces to come together and we are finally here!

Today, we have the data-collection devices and the infrastructure to successfully empower patients and enhance research opportunities.

We can see the potential to monitor health in new ways with wearable devices and apps on mobile.

In the near future we will be able to completely customize healthcare with the use of genomics data and proactively diagnose health issues before they become expensive to treat.

