#WeAreNotWaiting

@sensotrend

TRACK AND LEARN

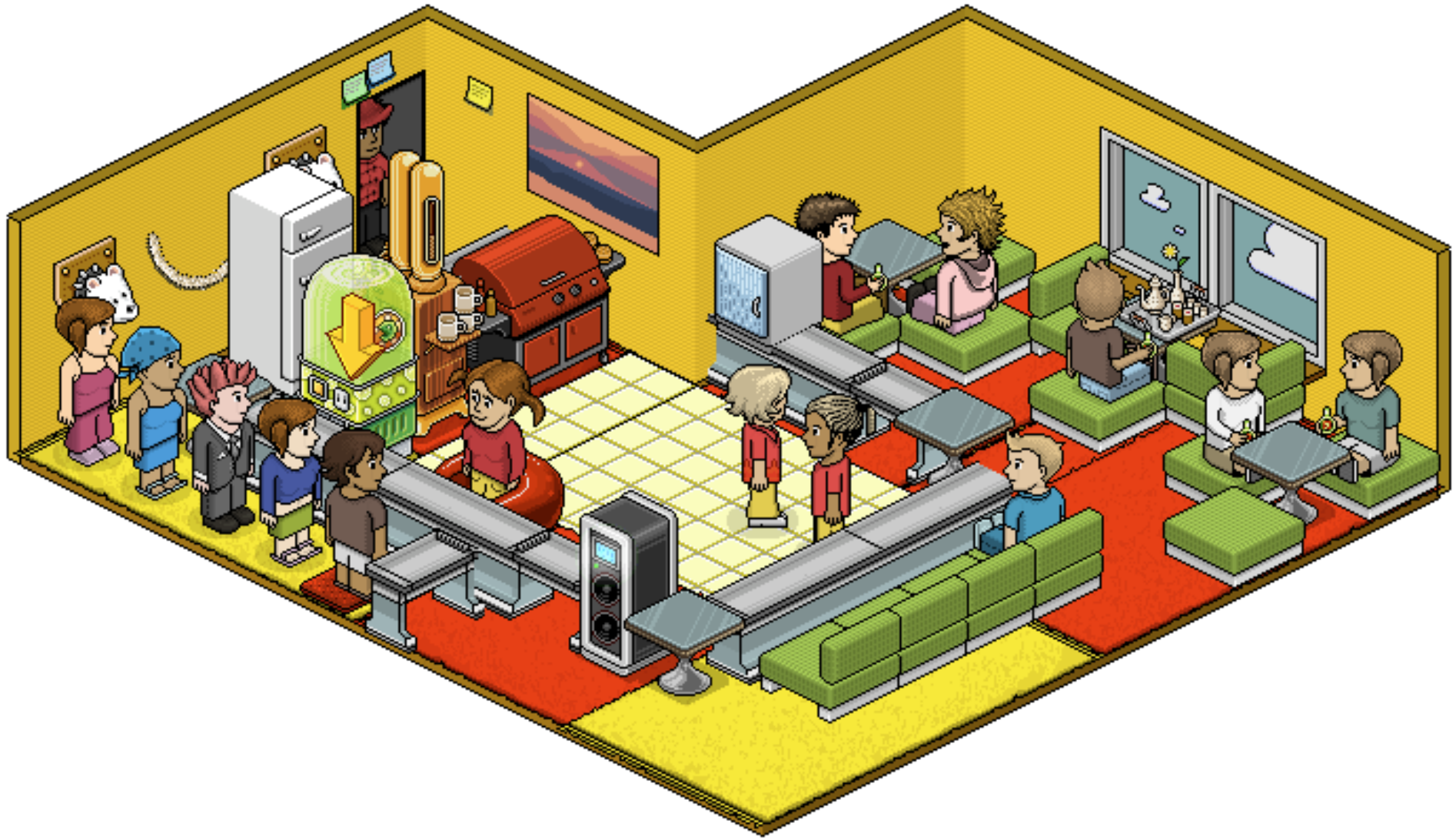
NIGHTSCOUT

#WeAreNotWaiting

Hi!

Sulka Haro

I hack pancreases as my hobby

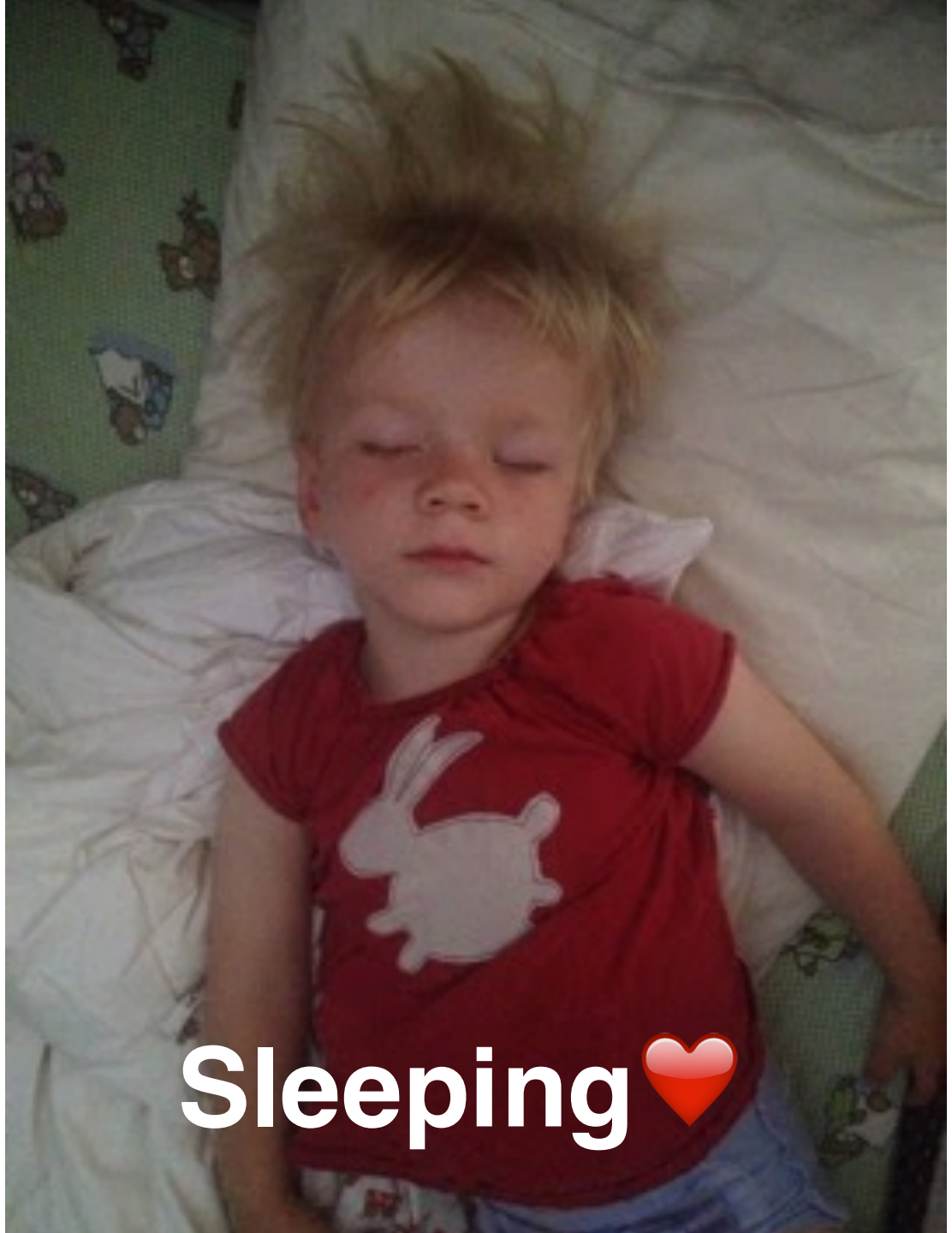


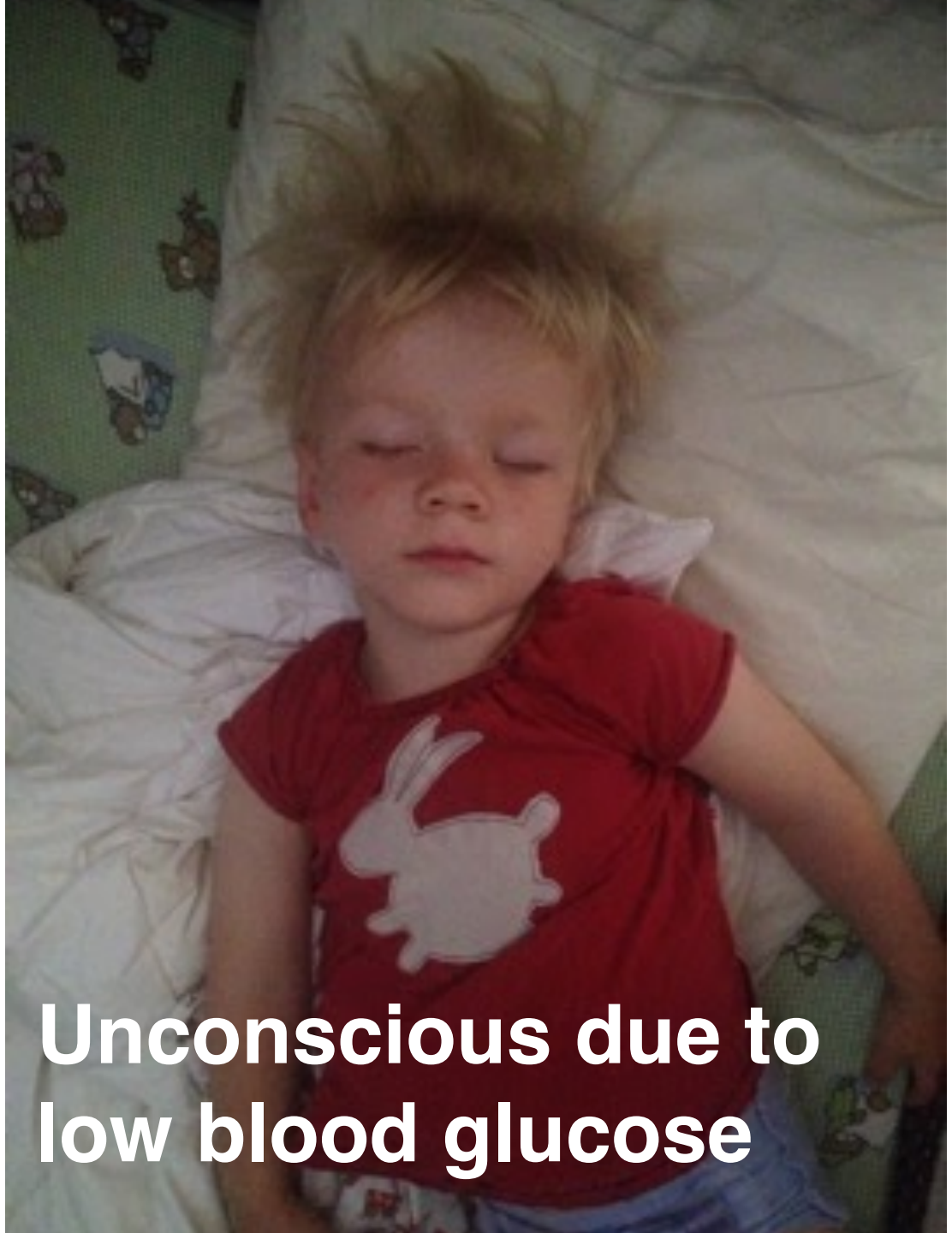
MakieLab

Manage your own fashion lab!

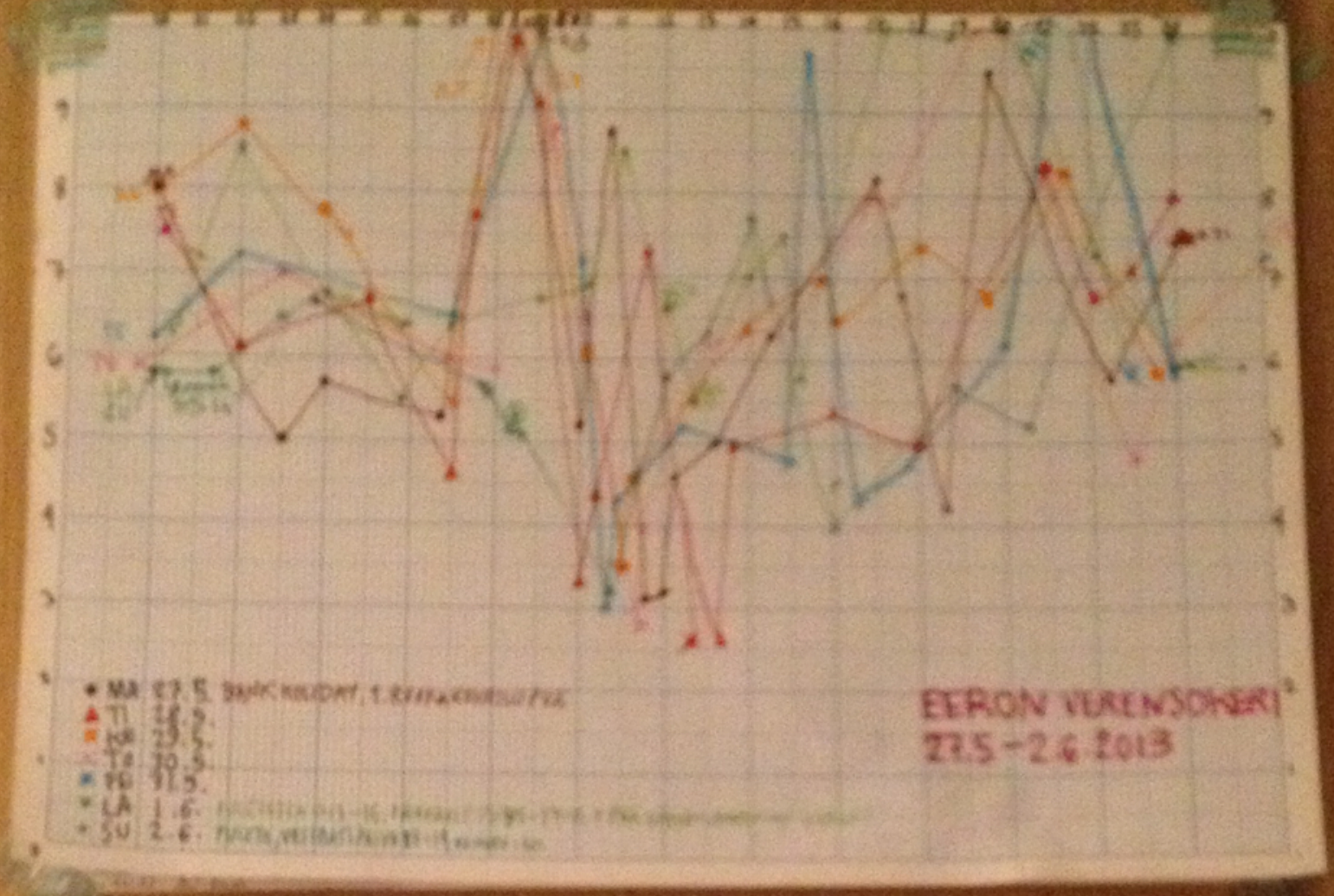
76
TAGE
IRIT

12:14PM
95
mg/dL

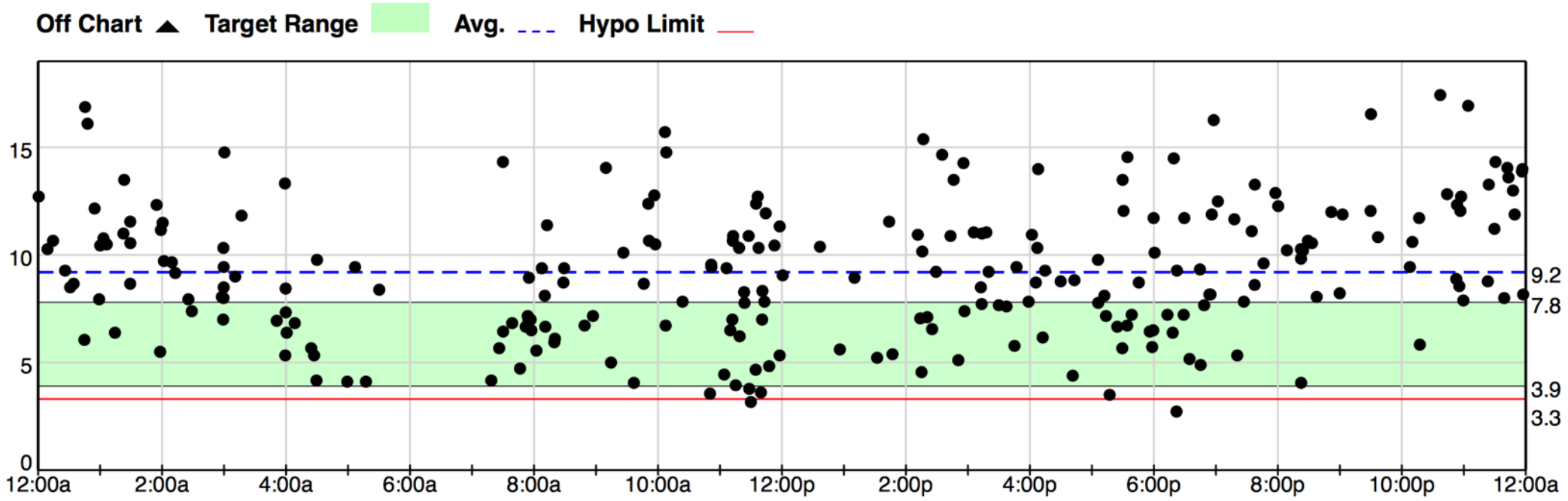

Sleeping❤️


Unconscious due to
low blood glucose

HEROES

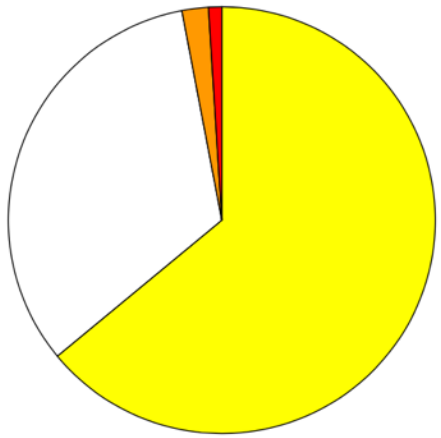

EERON VERENSOHERI
27.5 - 2.6 2013

Readings (mmol/L)



Distributions and Statistics

	Readings	Percent
In Range (3.9 - 7.8)	81	33%
Above (> 7.8)	155	64%
Below (3.3 - 3.8)	4	2%
Hypo (< 3.3)	2	1%
Total Readings	242	



	mmol/L
Average BG	9.2
High BG	17.4
Low BG	2.7
Std. Dev.	3.1

“Something went wrong 2 weeks ago.”

to learn, humans need feedback in real time

9:41 AM
100%
Tuesday
10
Messages
Calendar
Photos
Camera
Weather
Clock
Maps
Videos
Notes
Reminders
Stocks
Game Center
Newsstand
iTunes Store
App Store
Passbook
Compass
Settings
Phone
Mail
Safari
Music

Current Glucose is 108

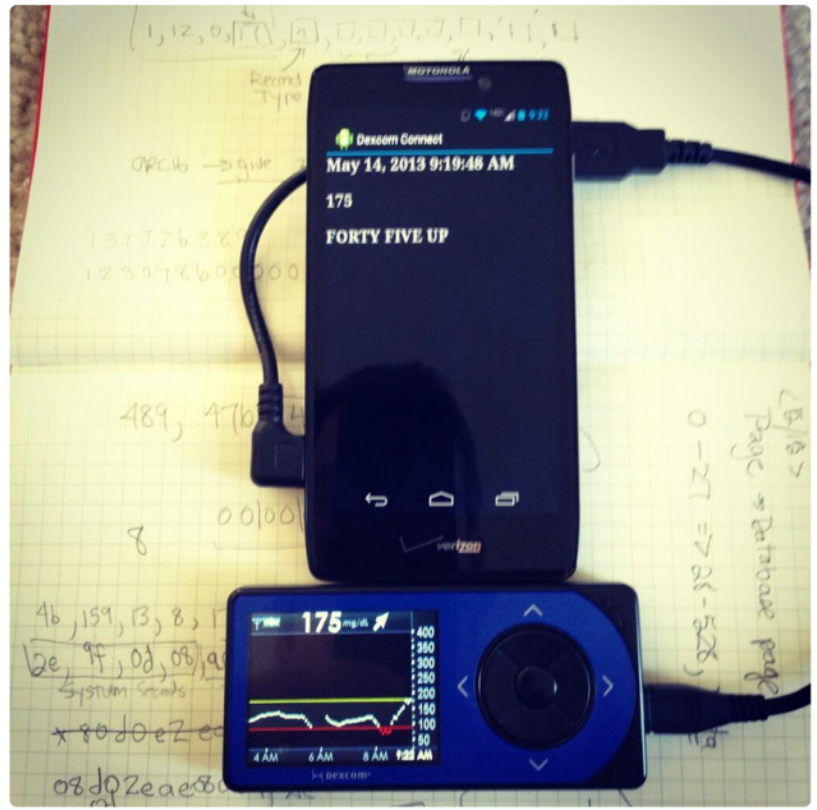
John Costik 14 May 13
@jcostik

Got E's phone, app is getting data from @dexcom G4. Will add features for a super safe kindergarten year #T1D
pic.twitter.com/7G5n06VzSg

John Costik Follow
@jcostik

Now getting all the important CGM data, and uploading to the cloud. 24x7 access to E's BG #T1D @Integ_Diabetes
pic.twitter.com/ZNIOjuunto

4:48 PM - 14 May 2013



1 2

John Costik
@jcostik

Following

@txtngmypancreas here it is, my son's cgm data 24/7, from anywhere, iOS/Android/Web, too. #wearenotwaiting

RETWEETS 7 LIKES 9

9:13 PM - 23 Jan 2014

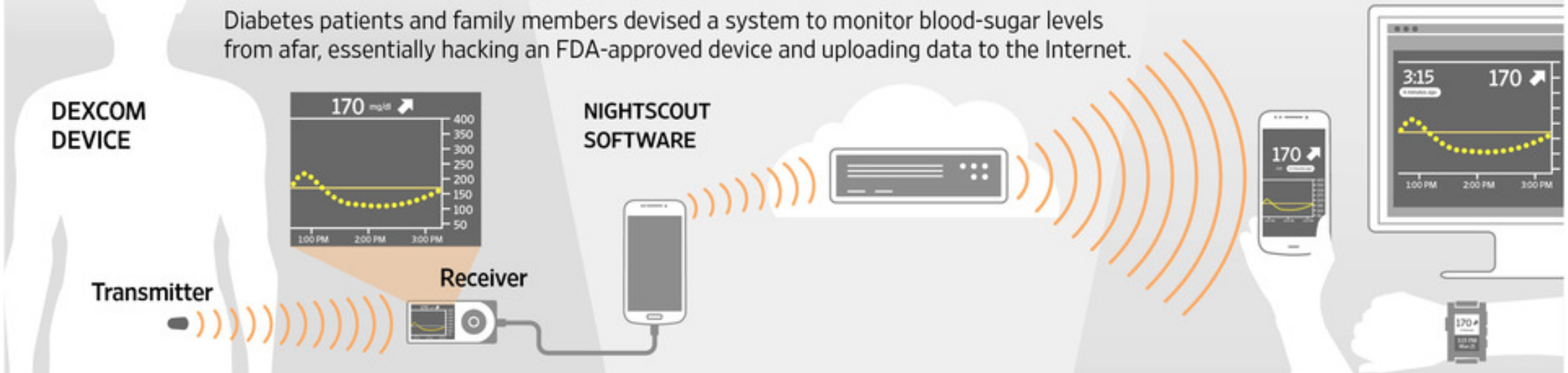
Chili, NY

#wearenotwaiting

2014

Do-It-Yourself Medical Monitor

Diabetes patients and family members devised a system to monitor blood-sugar levels from afar, essentially hacking an FDA-approved device and uploading data to the Internet.



1 A transmitter on the body gathers glucose-level data every five minutes and...

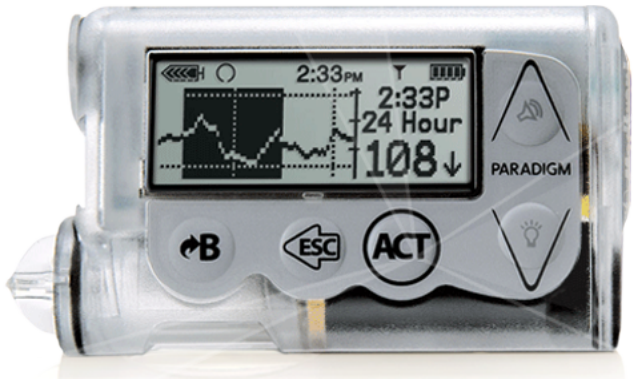
2 ...transmits them to a receiver for display. This works only if the receiver is within 20 feet of the transmitter.

3 To monitor from afar, a smartphone with NightScout software is connected to the receiver. The software downloads the glucose data and uploads it to a server.

4 The data is gathered by a customized website and displayed. Almost any device with access to the Internet and a Web browser can view the data.

Sources: Dexcom; NightScout

The Wall Street Journal

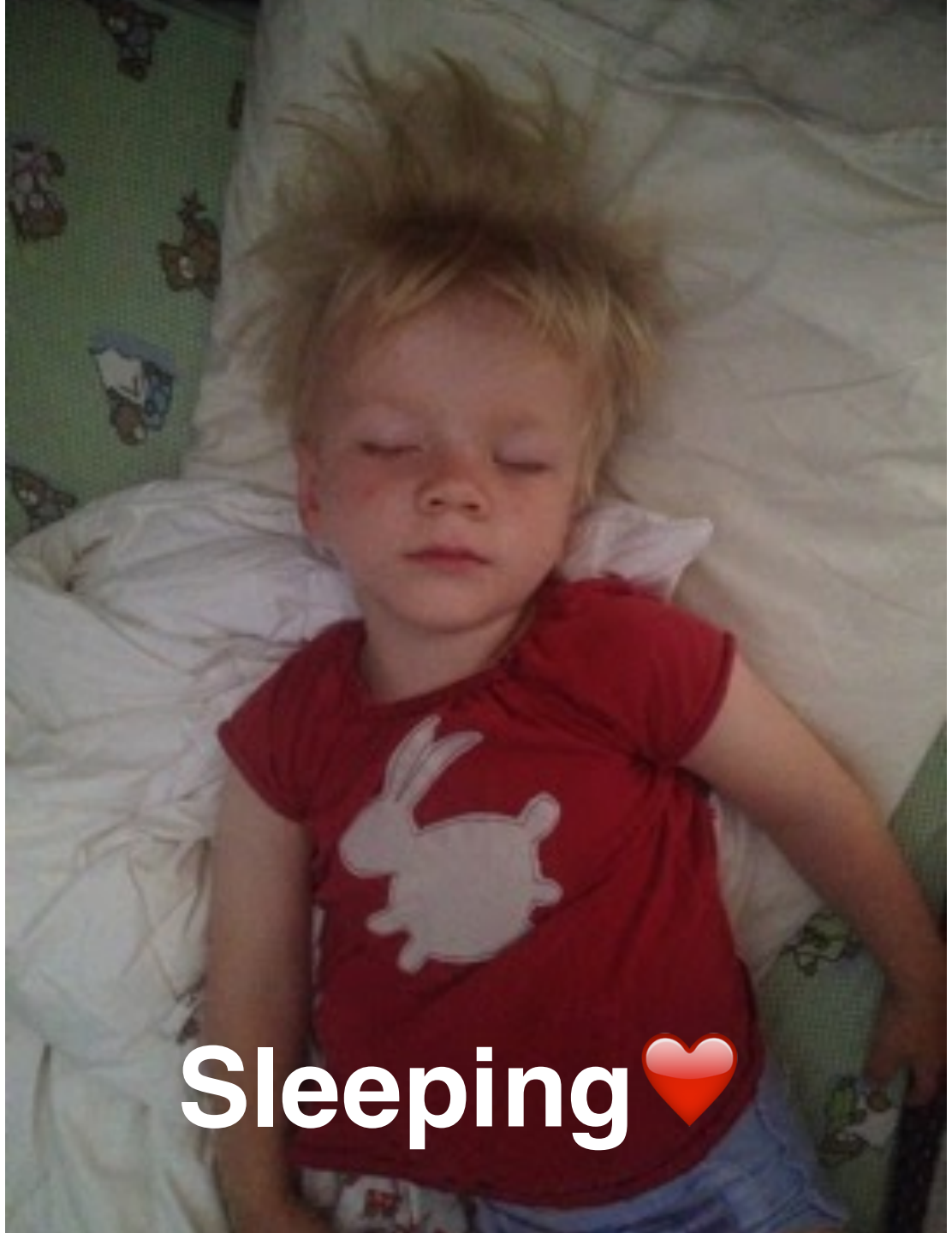

2:33PM
2:33P
24 Hour
108
PARADIGM
B
ESC
ACT

202 mg/dL
400
350
300
250
200
150
100
50
9:00 AM
10:00 AM
11:00 AM
11:30 AM
Dexcom

Nightscout
17:23
1 min ago
5.1
-0.2 mmol/L, BGI: -0.1
22
15
10
6
4
3
2
13:00
14:00
15:00
16:00
17:00
18:00
19:00
20:00
Tue 30
Wed 31
2015
Fri 02

play in the yard
stay overnight at friends
uninterrupted play

4.1 -0.1
-0.1 u
0u/h -0.25 (16) 50%
19:35


Sleeping❤️

Sleeping❤️

Full sources available!

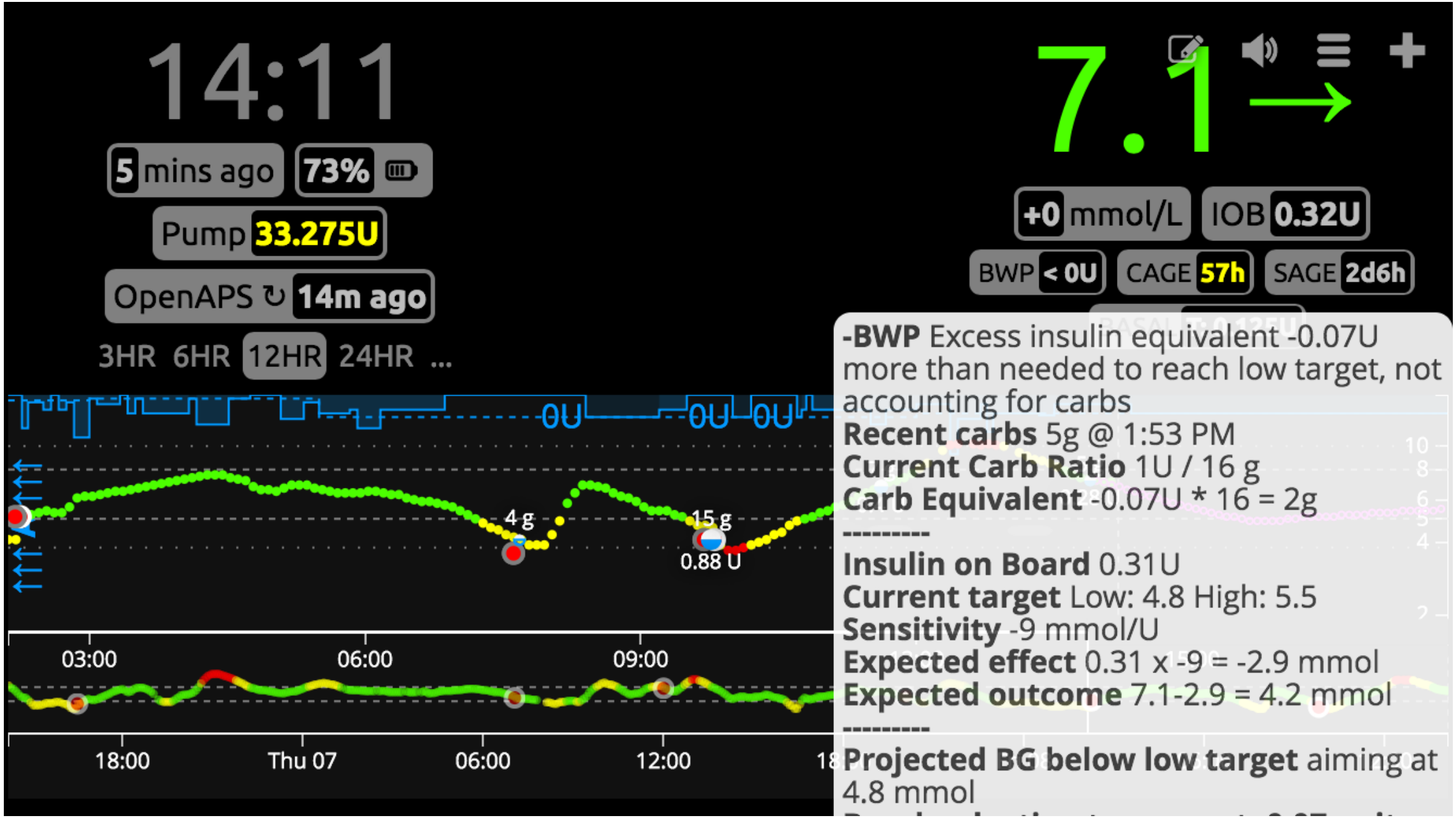
Does this mean something?

https://github.com/nightscout/cgm-remote-monitor/

from user to *developer*

Nightscout is the **#1 platform for real-time diabetes data visualization**

grown since to a full platform: **tens of companion apps and device integrations**


14:11
5 mins ago
73%
Pump 33.275U
OpenAPS ↻ 14m ago
3HR 6HR 12HR 24HR ...
7.1
+0 mmol/L
IOB 0.32U
BWP < 0U
CAGE 57h
SAGE 2d6h
0U
0U
0U
4 g
15 g
0.88 U
03:00
06:00
09:00
18:00
Thu 07
06:00
12:00
-BWP Excess insulin equivalent -0.07U more than needed to reach low target, not accounting for carbs
Recent carbs 5g @ 1:53 PM
Current Carb Ratio 1U / 16 g
Carb Equivalent -0.07U * 16 = 2g

Insulin on Board 0.31U
Current target Low: 4.8 High: 5.5
Sensitivity -9 mmol/U
Expected effect 0.31 x -9 = -2.9 mmol
Expected outcome 7.1-2.9 = 4.2 mmol

Projected BG below low target aiming at 4.8 mmol

8000 installations, >90% by non-technical people

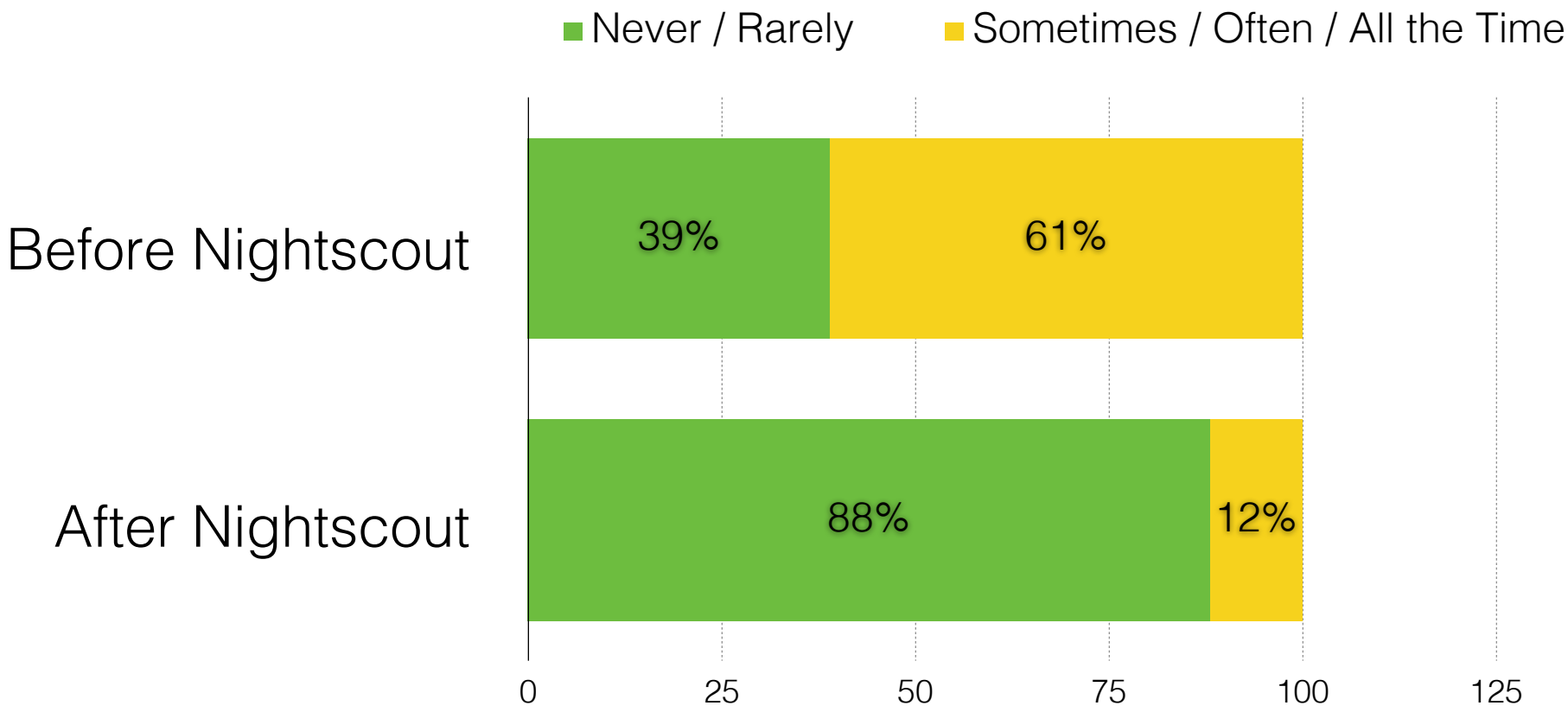
20,000 member Facebook support group paying it forward

“Nightscout study”

Joyce Lee, MD, MPH
Associate Professor, University of Michigan Medical School

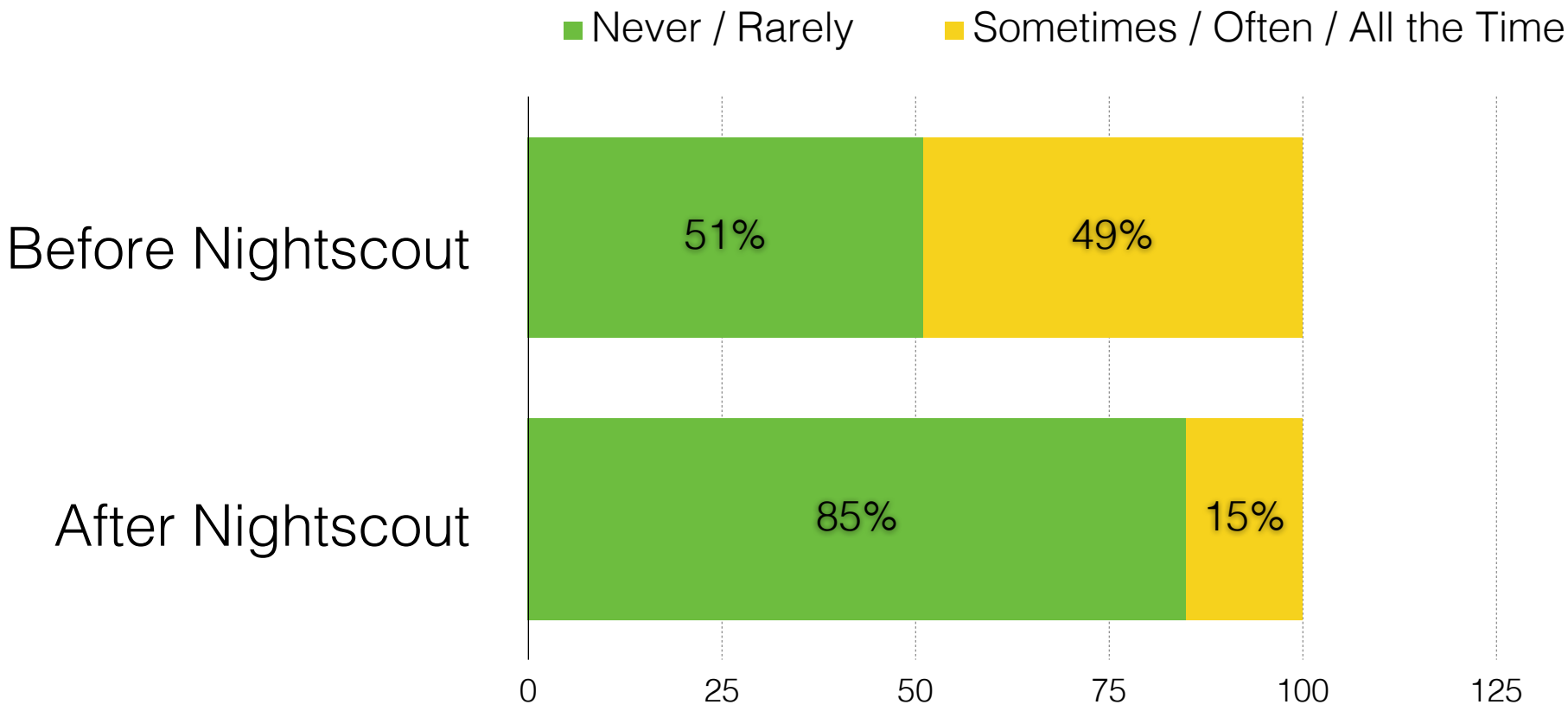
Robert P. Kelch, MD
Research Professor of Pediatrics

Diabetes kept me from doing normal activities



Source: Dr Joyce Lee, Univ. Michigan

Diabetes kept me from spending time at work



Source: Dr Joyce Lee, Univ. Michigan

HbA1c average drop of over 1%

Huge! *Massively* drops the probability of long-term complications for the users

real-time access to blood glucose data

by **diabetics themselves**

fundamentally transforms diabetes management

~~I hack pancreases as my hobby~~

I help people with a broken pancreas see what their bodies are up to

Living with ~~DIABETES~~

NIGHTSCOUT
#WeAreNotWaiting

#wearenotwaiting

Thank you!

http://nightscout.info

@sulka
sulka@sulka.net

Stephanie Bonas

Stephanie Bonas

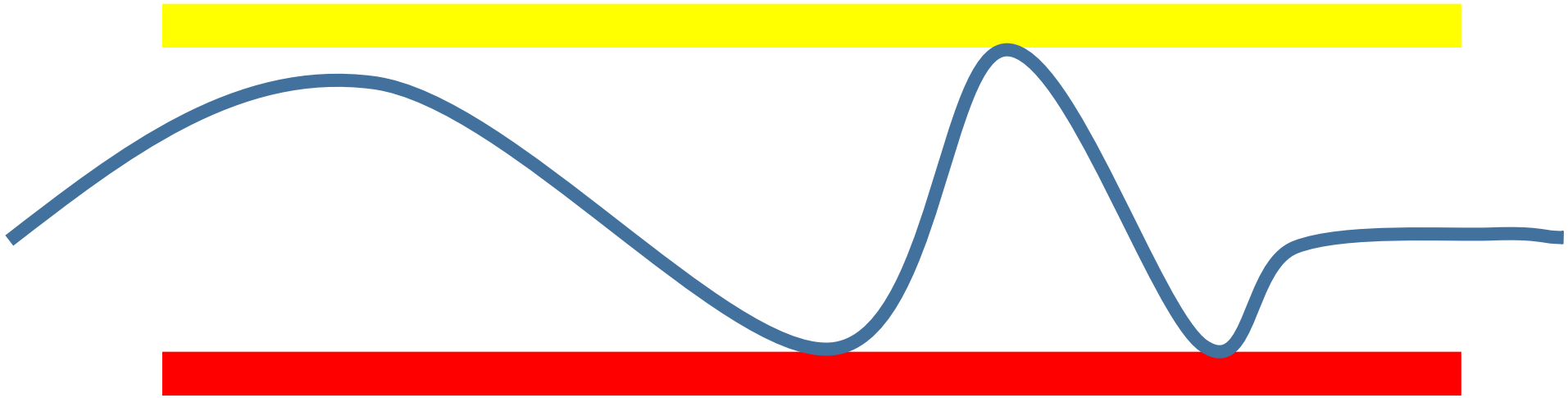
Stephanie Bonas

#OpenAPS

Closing the loop:

@DanaMLewis

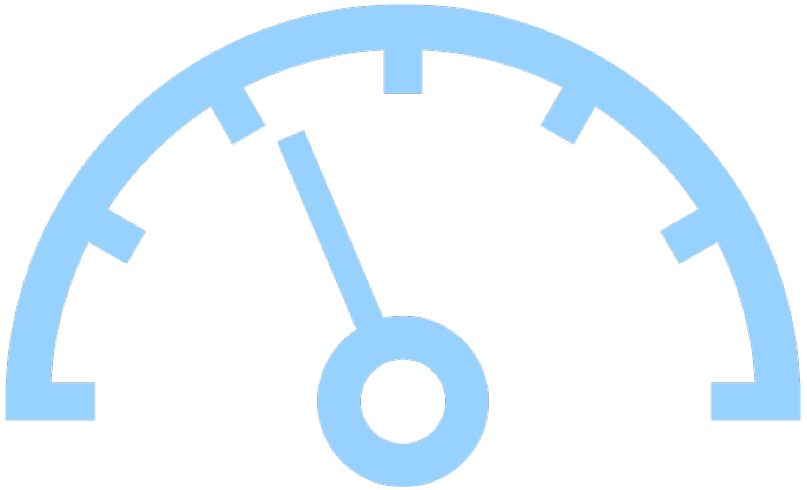
Food, hormones, sickness, stress



Insulin, exercise, sickness, stress

@DanaMLewis

Cruise control makes it easier to drive your target speed.



@DanaMLewis

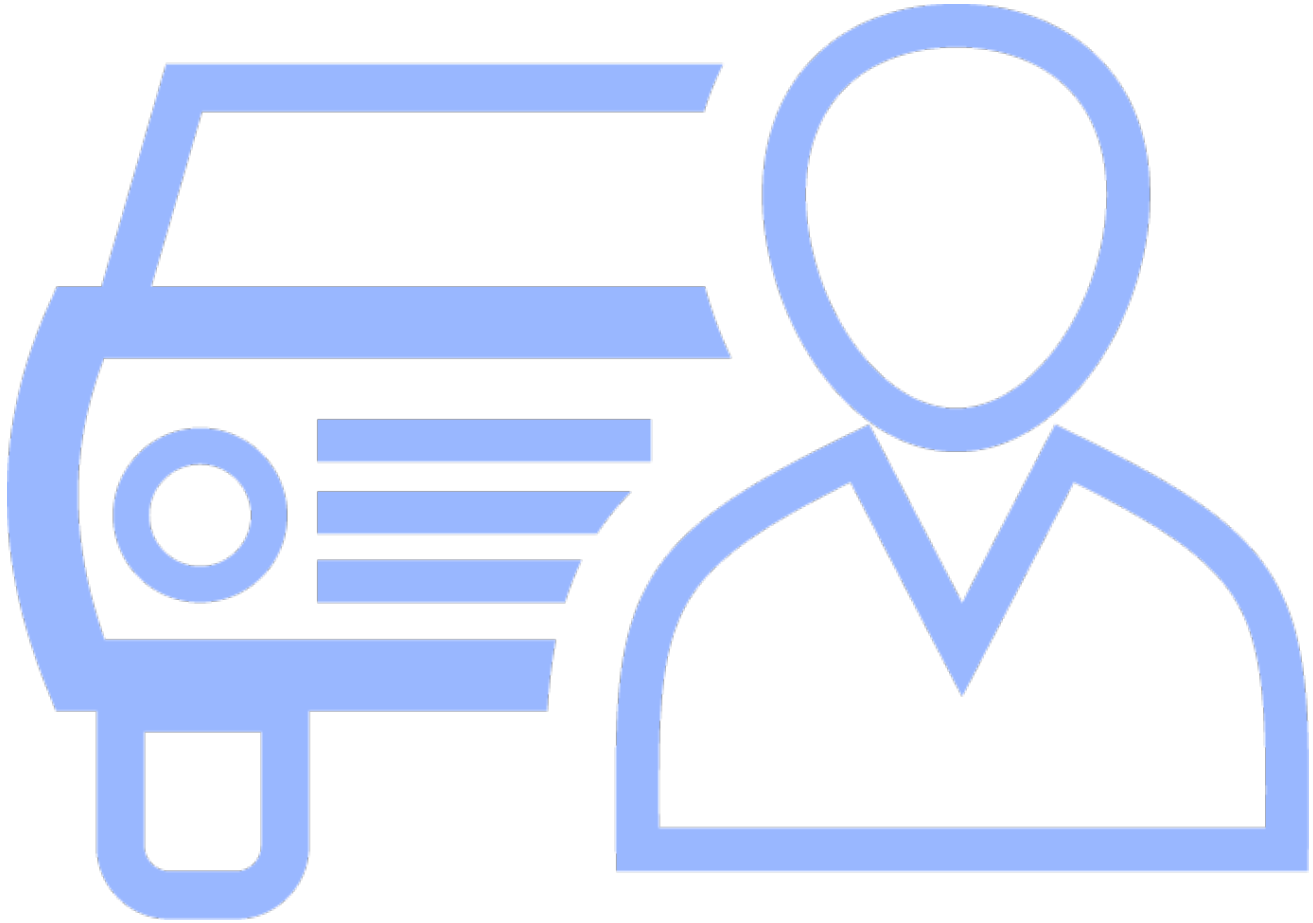
In diabetes, insulin is the “gas” pedal.

@DanaMLewis

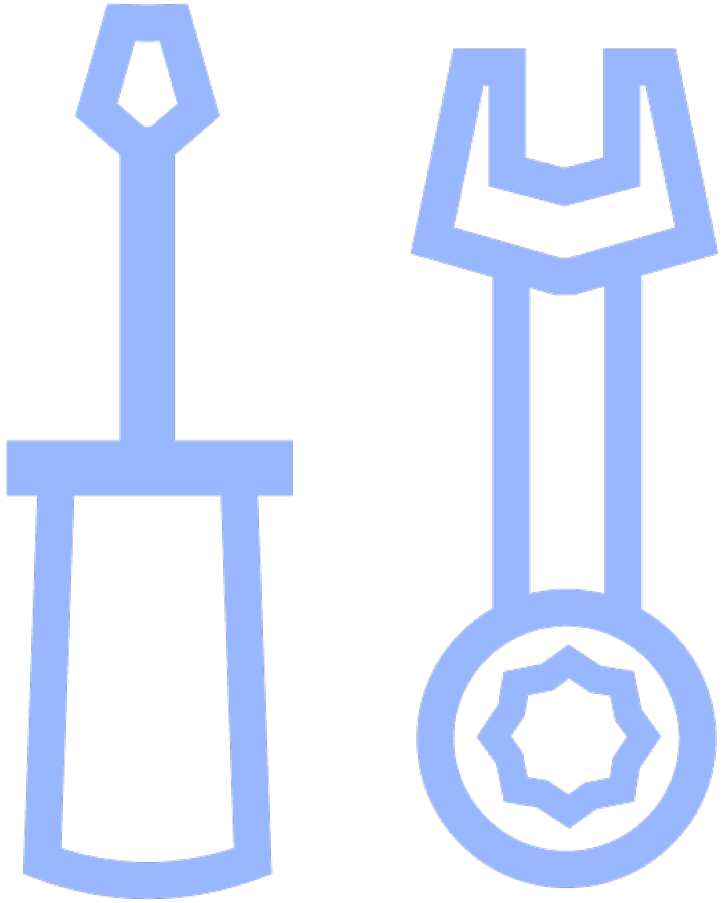
@DanaMLewis

An artificial pancreas is the closest thing to "cruise control" for diabetes.

…But an artificial pancreas is not yet commercially available.



@DanaMLewis

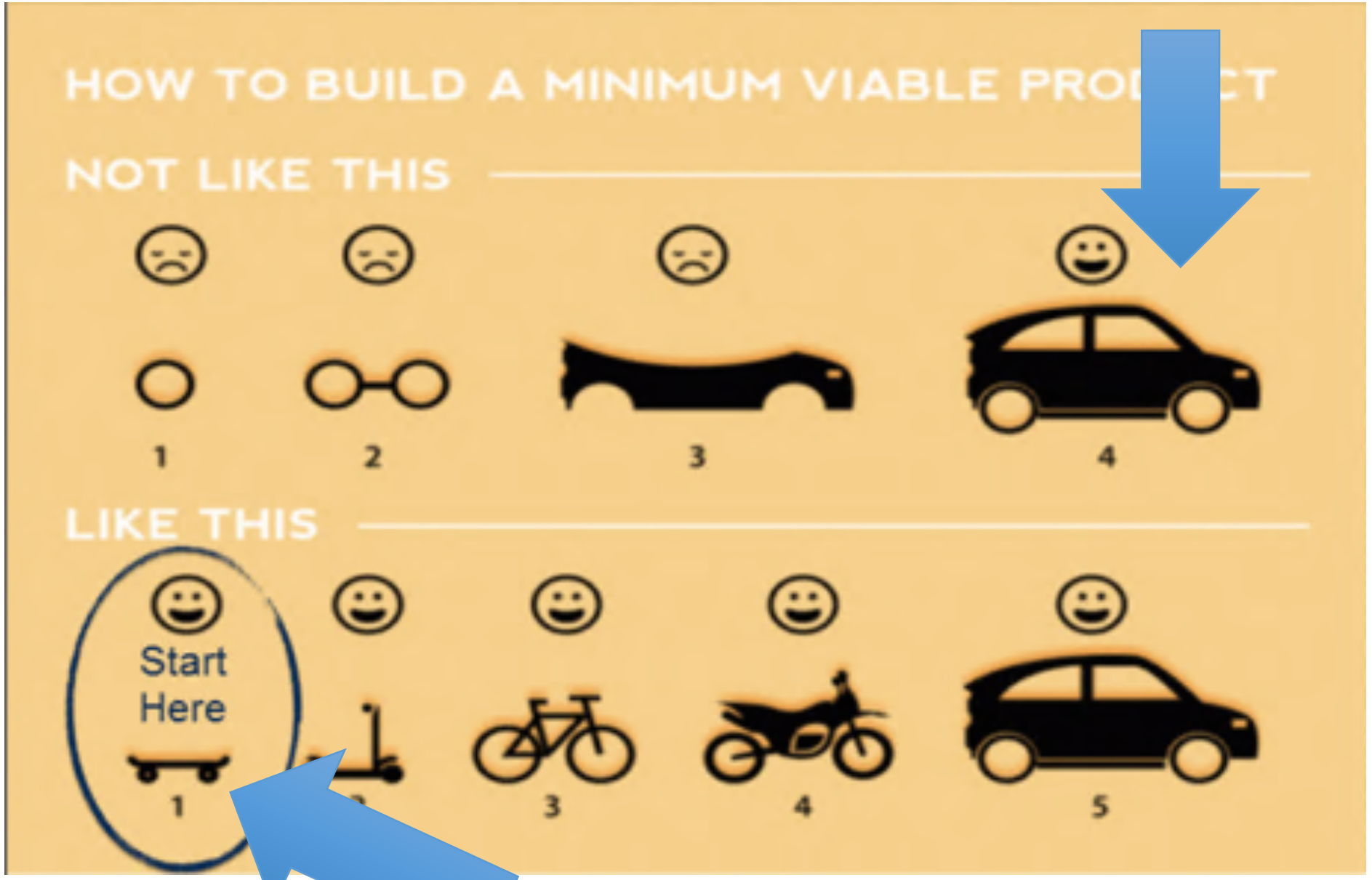


The current tools are not perfect….

….and not interoperable.

@DanaMLewis

Traditional innovation

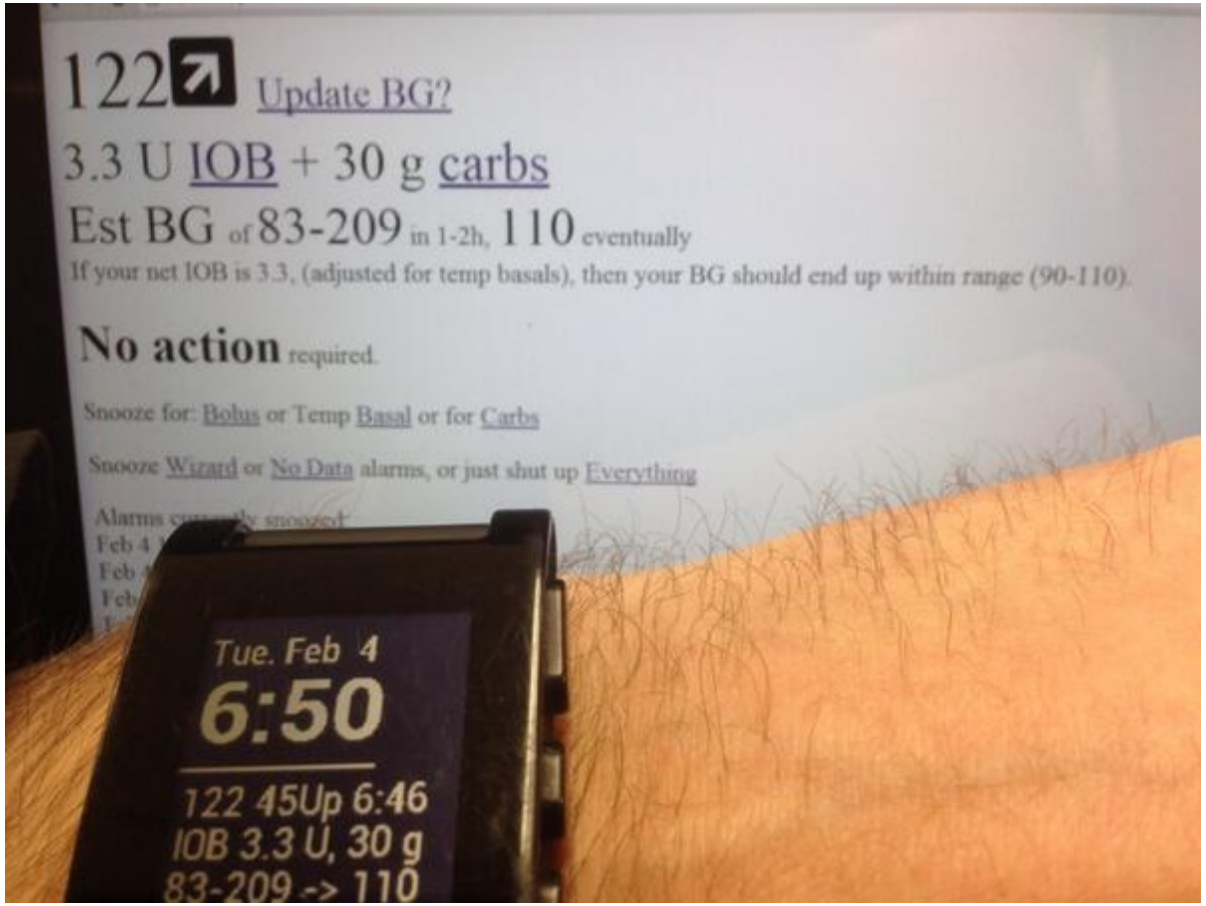


User-driven innovation

All I wanted (at first): louder CGM alarms

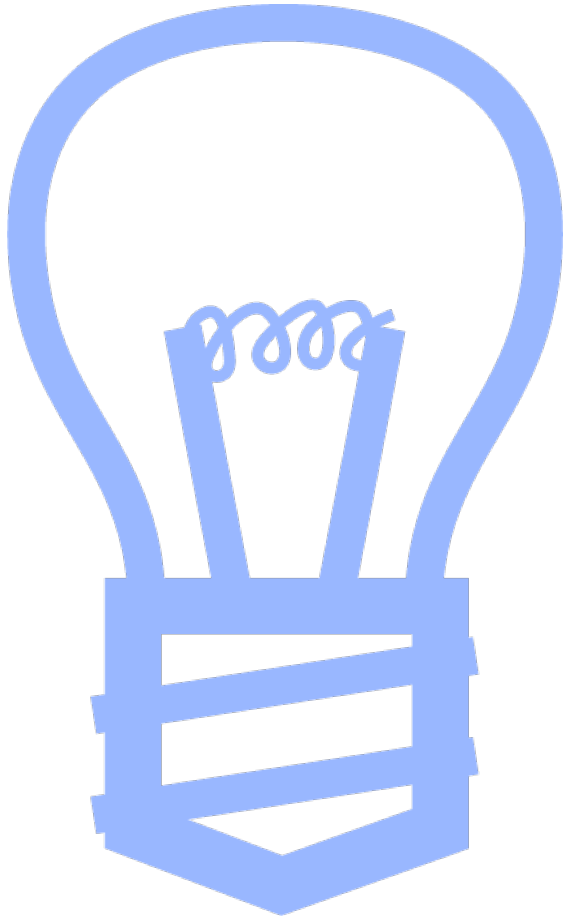
@DanaMLewis

Where I ended up: an “open loop”, smart alarm system with predictive recommendations

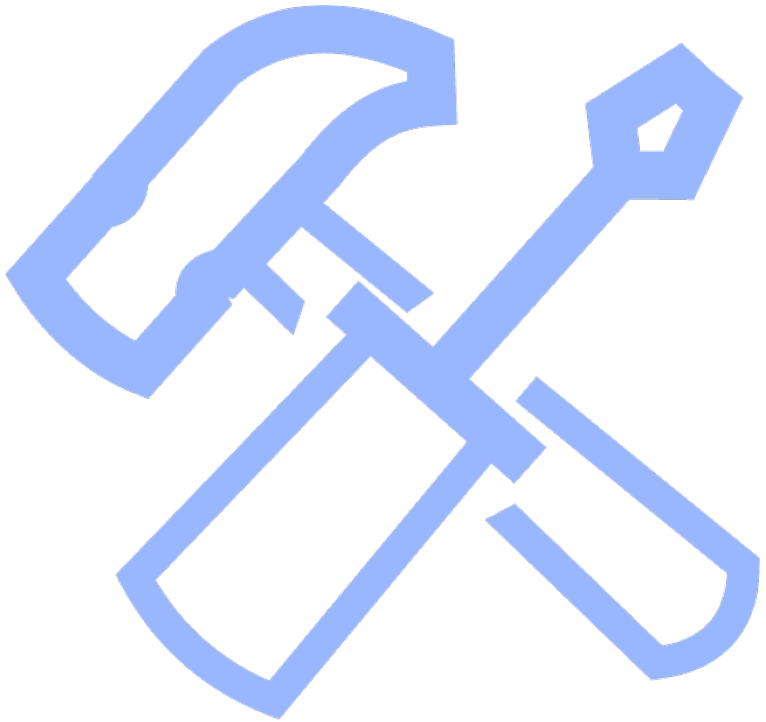


@DanaMLewis

What happens if we “close the loop”?



@DanaMLewis



We have in our pockets the tools needed for an “artificial pancreas”.

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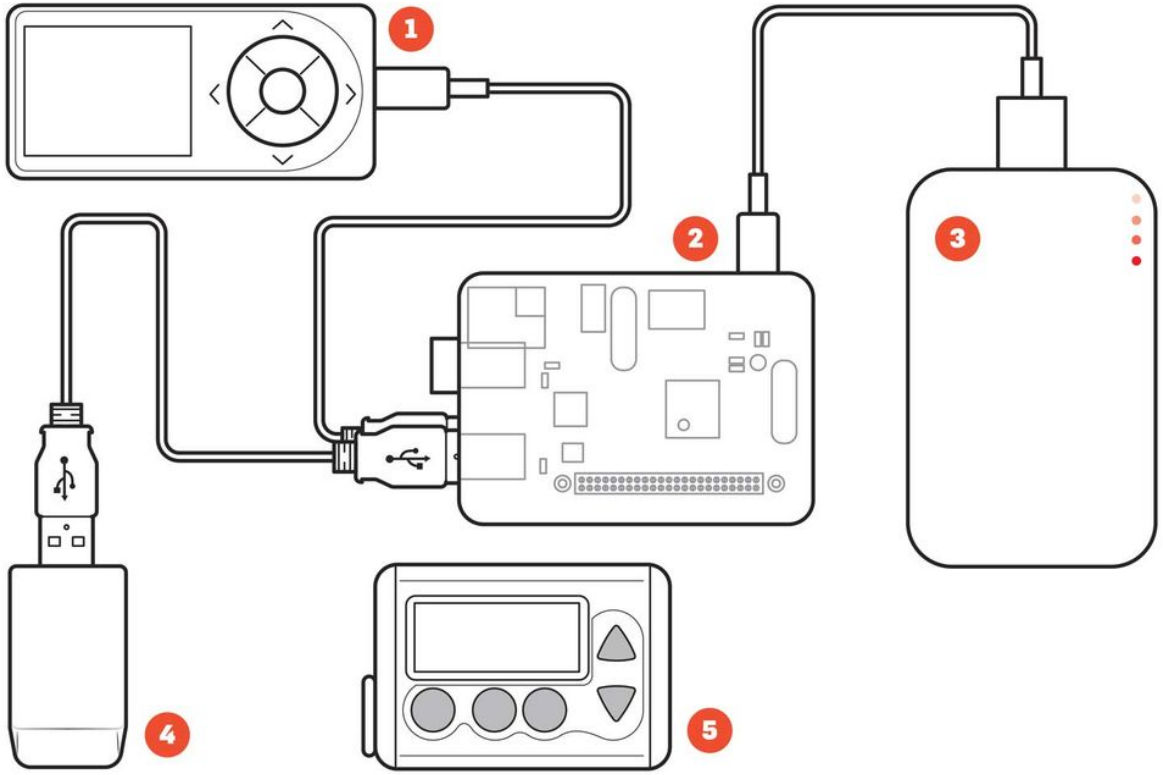
Components of an open source artificial pancreas

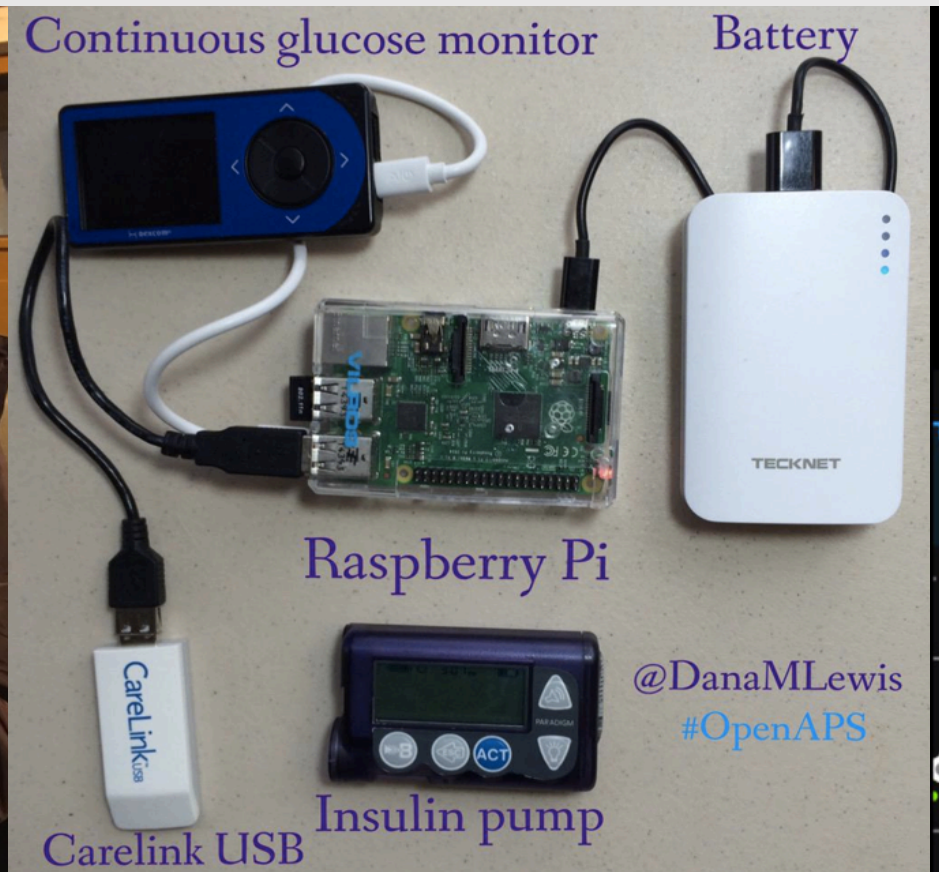


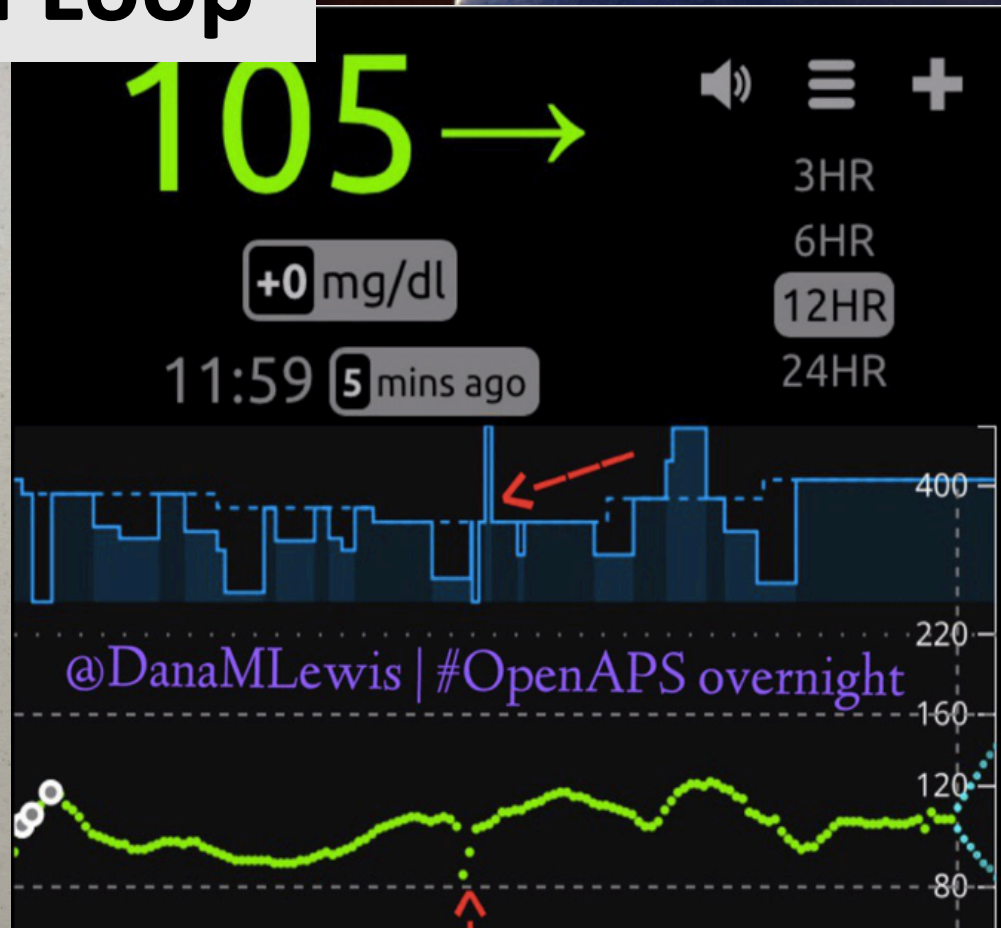
(Illustration by Clint Ford for Popular Science)

1. Continuous glucose monitor
2. Raspberry Pi (“controller”)
3. Battery
4. CareLink USB stick (“translator”)
5. Insulin pump

@DanaMLewis

Life with a DIY Closed Loop





#OpenAPS:

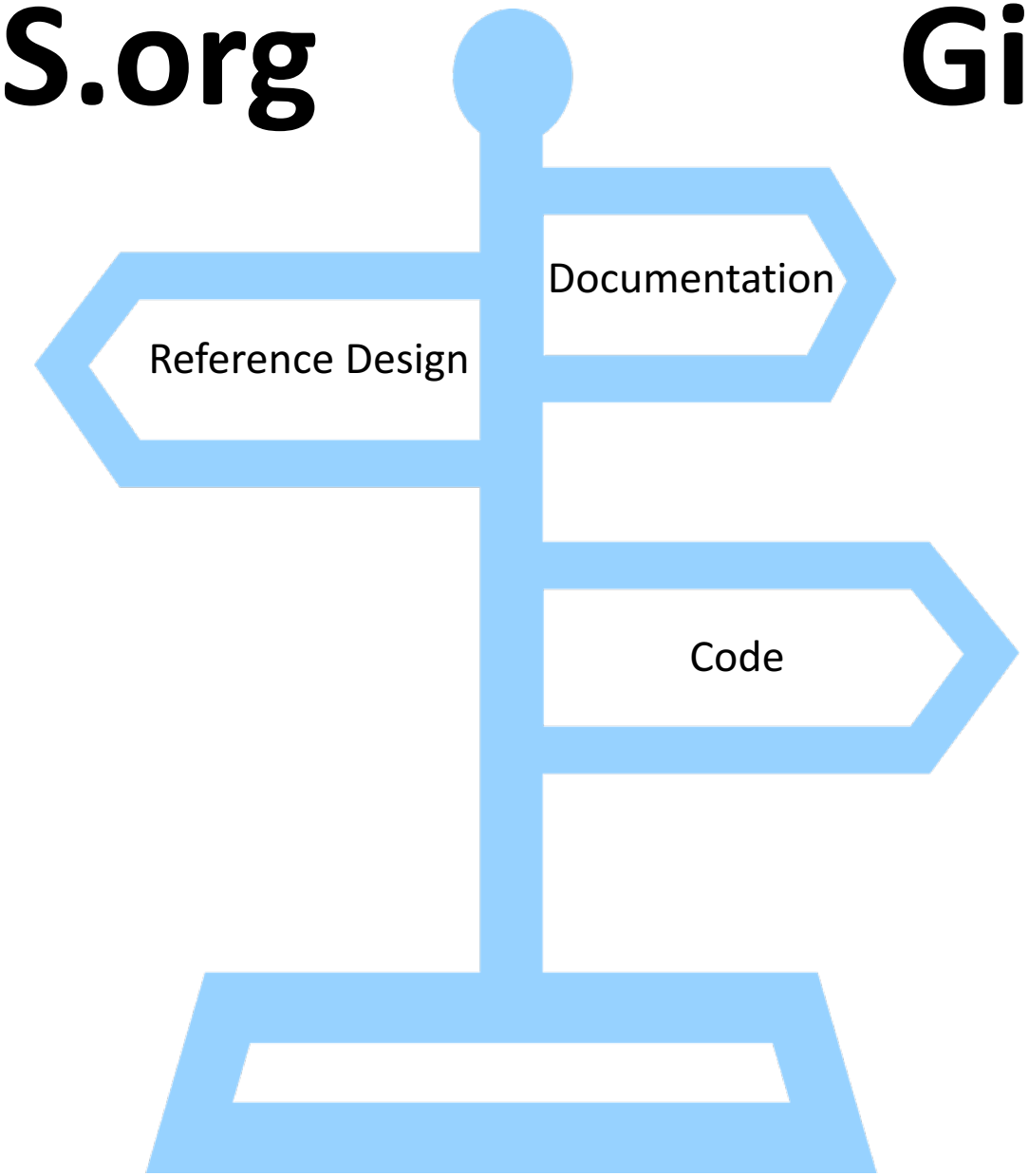
Taking the DIY, artificial pancreas from (n=1) to (n=1)*many by:

- Focusing on safety
- Limiting dosing ability in hardware and software
- Using same dosing calculations a person would use
- Responding (or not) to unexpected data
- Tolerating communication failures
- Failing back safely to standard device operation

@DanaMLewis

OpenAPS.org

Github.com/openaps



@DanaMLewis

(It's not "rocket science")

```
28
29  if (predBG < min) { // low-temp for 30m (to zero or as required to get predBG up to min)
30      var rate = Math.max(0, $basal-2*(min-predBG)/isf); // calculate required low-temp rate
31      var duration = 30; // always set temps to the minimum duration supported by the pump
32      if (! typeof currentTempRate === 'undefined' && rate < currentTempRate) {
33          setTemp(rate, duration);
34      }
35  } else if (predBG < target) { //cancel any high-temp; let any low-temp run
36      if (! typeof currentTempRate === 'undefined' && currentTempRate > basal) {
37          setTemp(0, 0); // cancel temp
38      }
39  } else if (predBG > max) { // high-temp as required to get predBG down to max (up to basal+highTempMax U/hr)
40      var rate = $basal + Math.min(highTempMax,2*(predBG-max)/isf)
41      if (! typeof currentTempRate === 'undefined' && rate > currentTempRate && iob < maxIOB) {
42          setTemp(rate, duration);
43      }
44  } else if (predBG > target) { //cancel any low-temp; let any high-temp run
45      if (! typeof currentTempRate === 'undefined' && currentTempRate < basal) {
46          setTemp(0, 0); // cancel temp
47      }
48  }
```

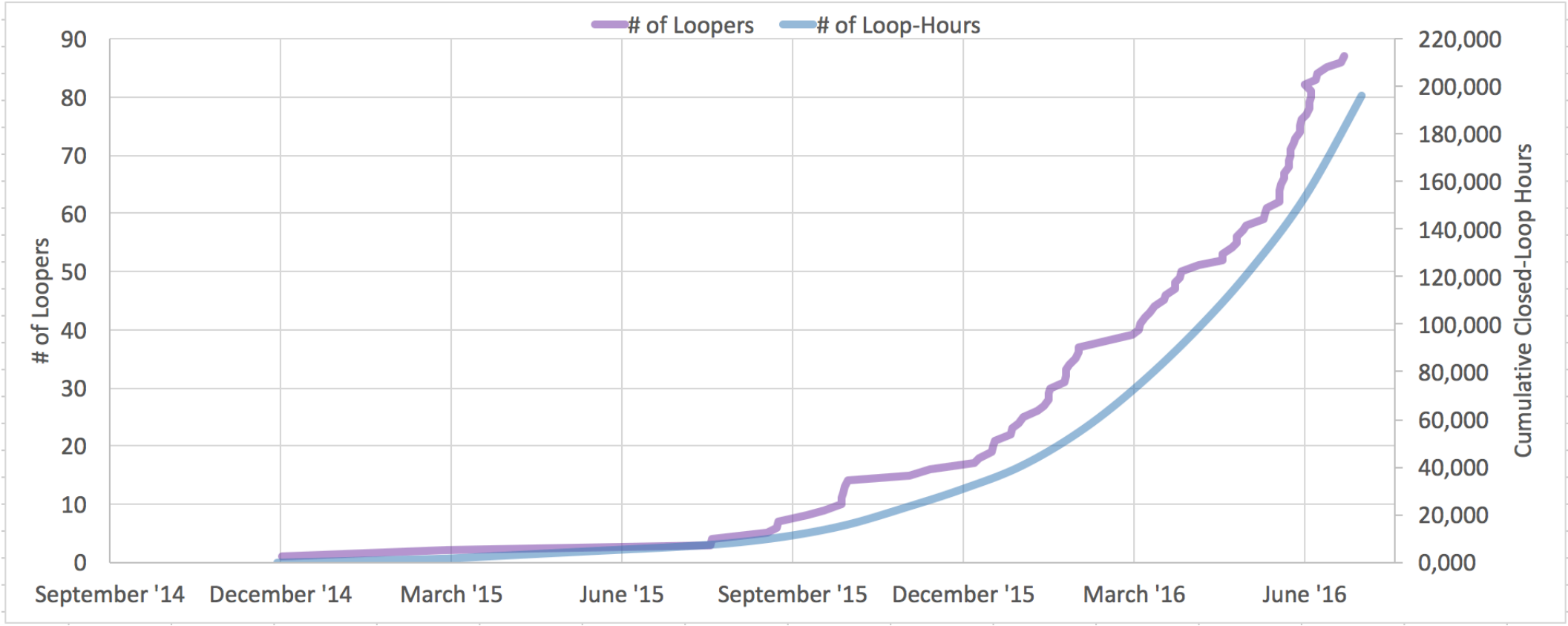
@DanaMLewis

Who is regulating this activity? Users are.

- Most users “test” their own medical devices.
- The QA approach is even stronger when utilizing open source tools made with/by/for the community.
- (Individual experiments with “off label” use of medical devices are not a regulated activity.)

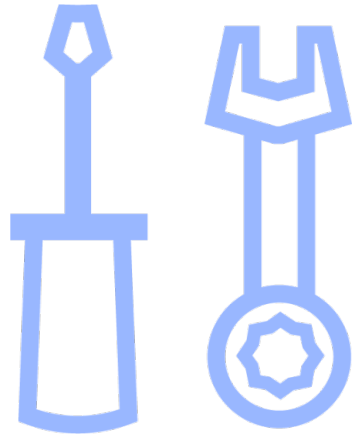
@DanaMLewis

#OpenAPS is now (n=1)*108+



@DanaMLewis

The future of #WeAreNotWaiting:



- We are not done yet. We still have diabetes, we still have other tools we can improve on.

- This will happen in other areas of healthcare.

- The healthcare industry will need to figure out how to deal with new sources of patient-generated health data.

@DanaMLewis

#WeAreNotWaiting

to change the future of healthcare.

Are you?

#OpenAPS |@DanaMLewis | OpenAPS.org

#WeAreNotWaiting

Doctors
Regulators
Deployment
Privacy, security
Effects on Industry

@mrinnetmaki @sulka @danamlewis @scottleibrand

#WeAreNotWaiting

Deep dive: Group Lounge Elissa 2 12.45-13.30