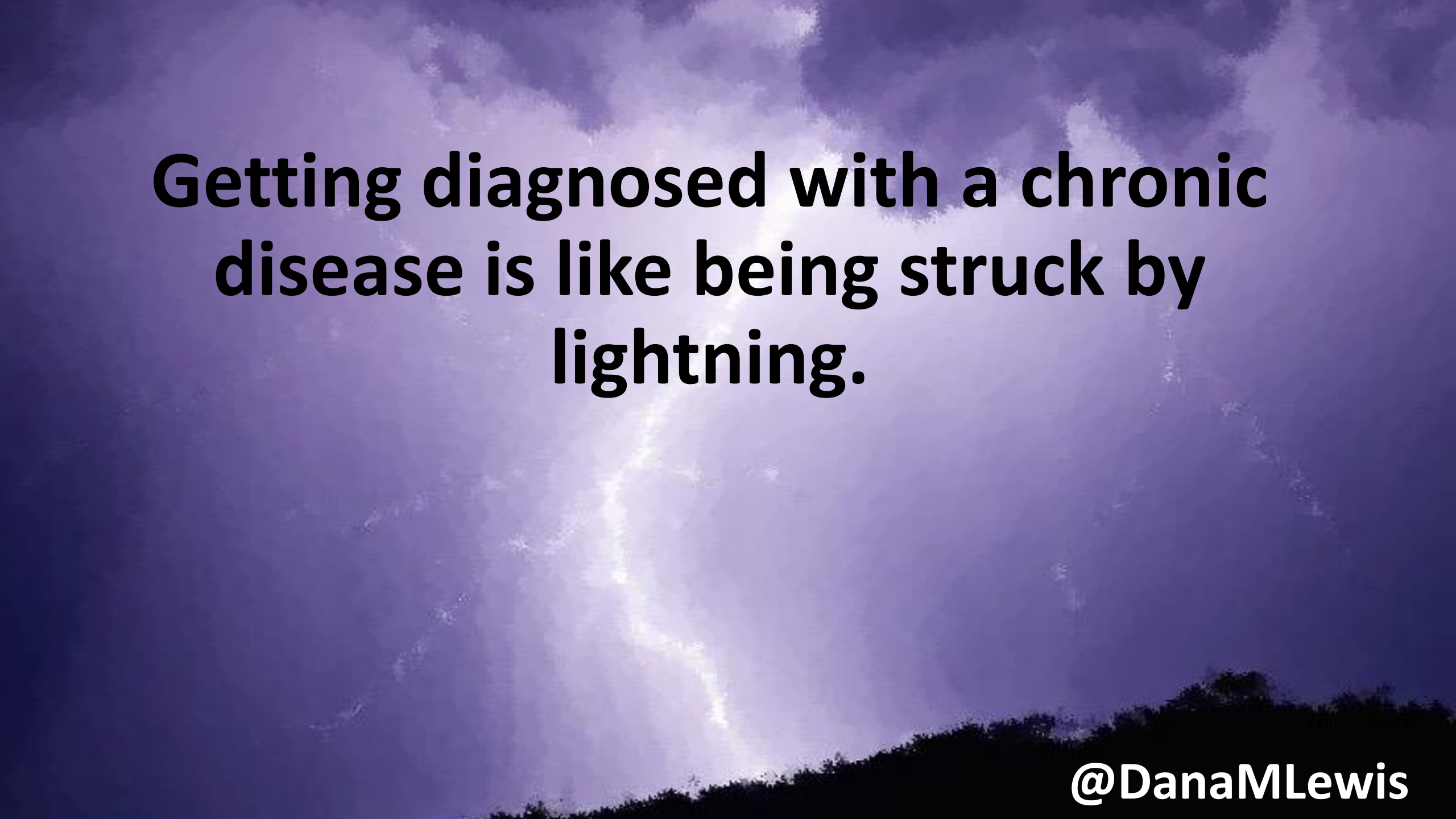
#WeAreNotWaiting

(Solving the problem as a patient)

@DanaMLewis


Getting diagnosed with a chronic disease is like being struck by lightning.
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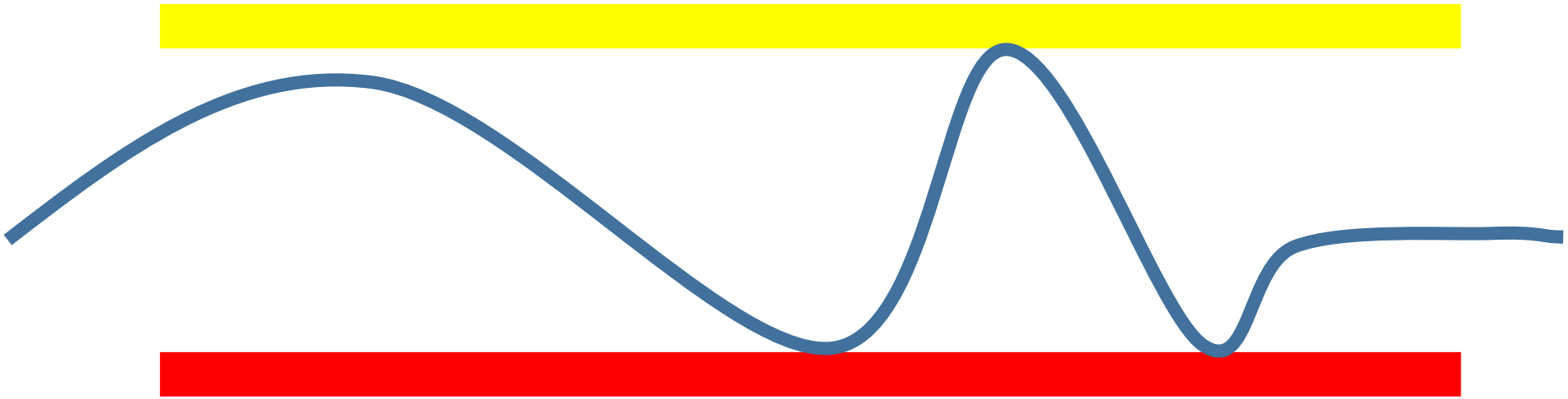
Food, hormones, sickness, stress



Insulin, exercise, sickness, stress

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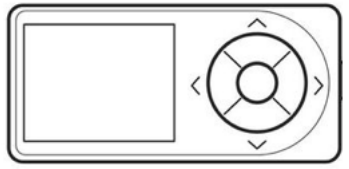
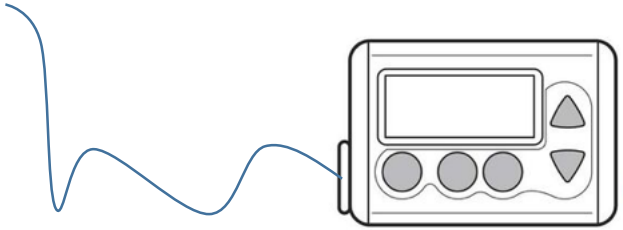
The current tools are not perfect….



Continuous Glucose Monitor (CGM)



Insulin Pump

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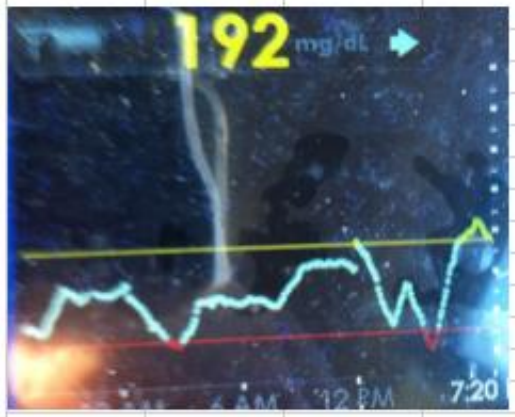
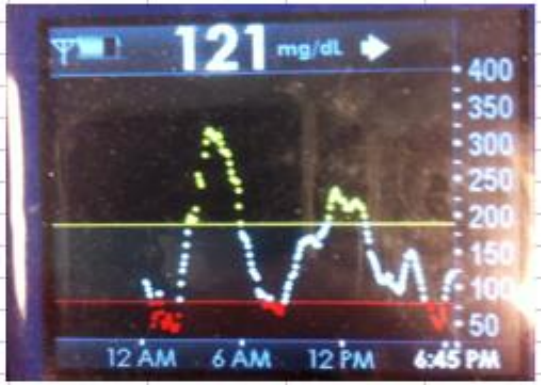
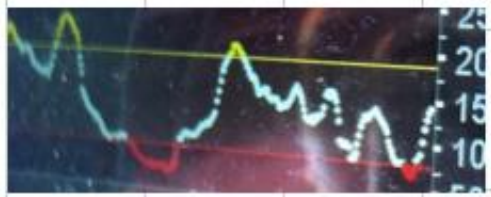
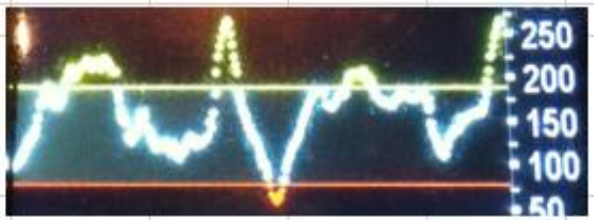
Leaving us often with this:

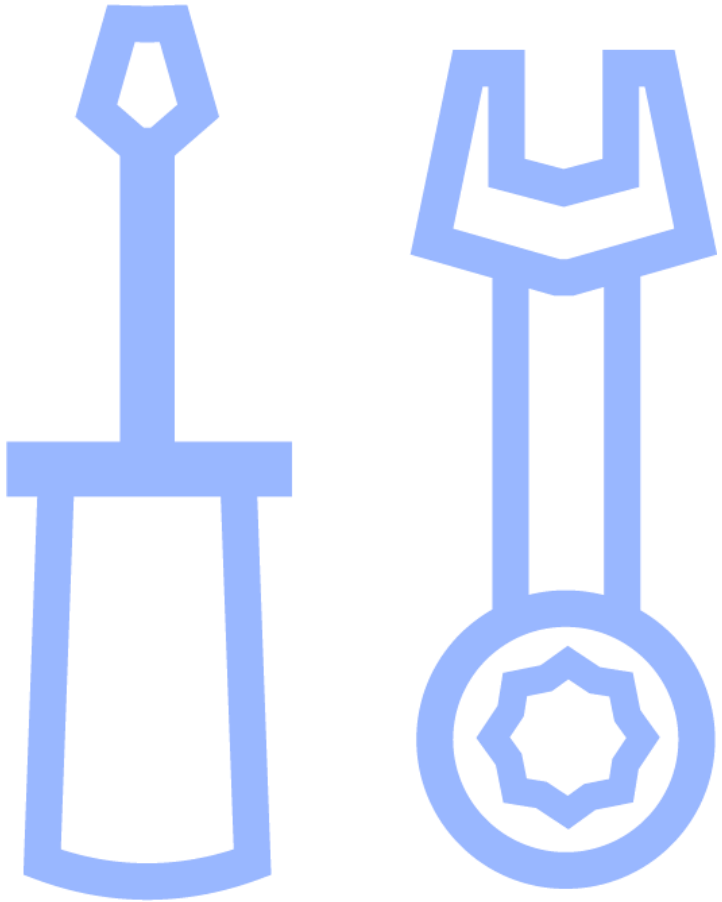








4-Jul	7-Jul
salad	banana
frozen dinner	hamburger, salad, ice cream
cheese & crackers	steak/rice/beans bowl
	7/8 - 4 mile run, transmitter died
5-Jul	9-Jul
bacon & eggs	bacon & eggs
chicken & rice	tomato soup
larabar & sausage	cheese & crackers
6-Jul	10-Jul
banana	yogurt
doritos	bacon & eggs
ham/cheese lettuce wrap with yogurt, cheetos	
steak & potato	chicken & rice fondue



If we can't change existing devices…

what if we could add *new* tools?

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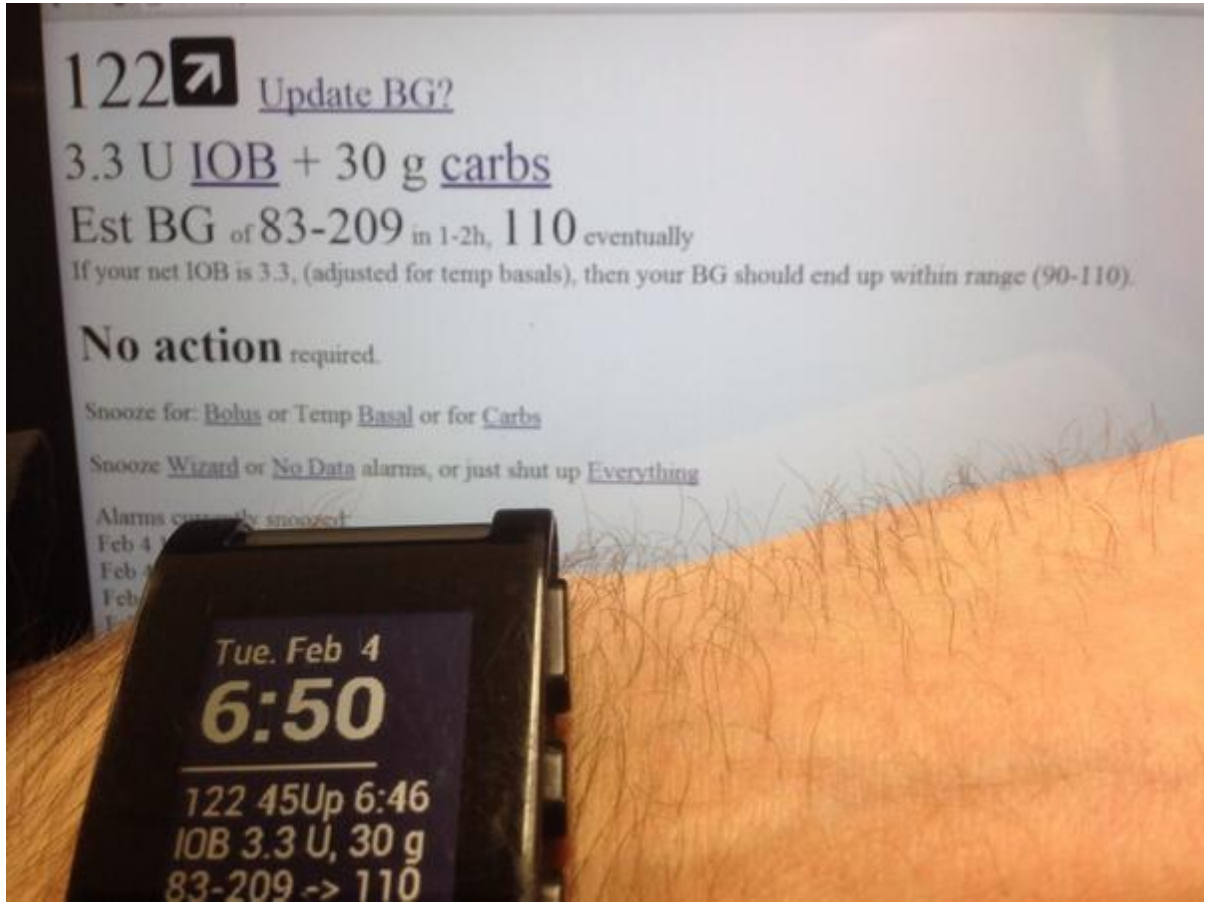
From reactive to predictive: an “open loop”



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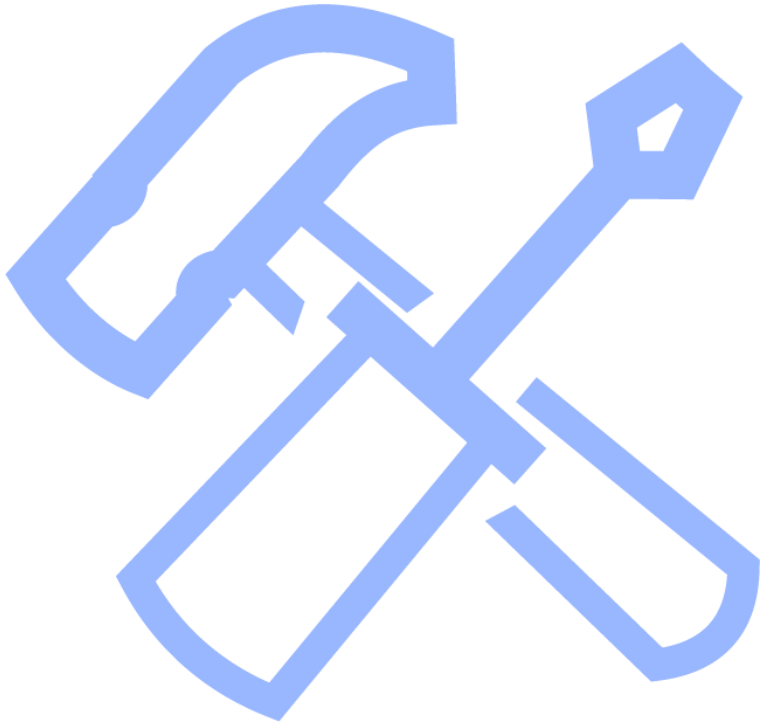

We already have in our pockets the tools needed for an “artificial pancreas”.

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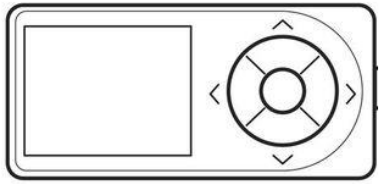
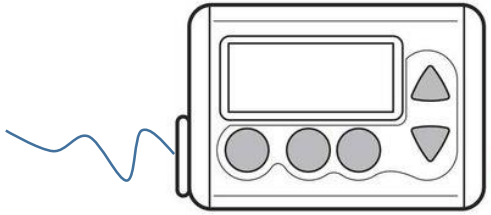
Components of an open source artificial pancreas



- Continuous glucose monitor



- Insulin pump

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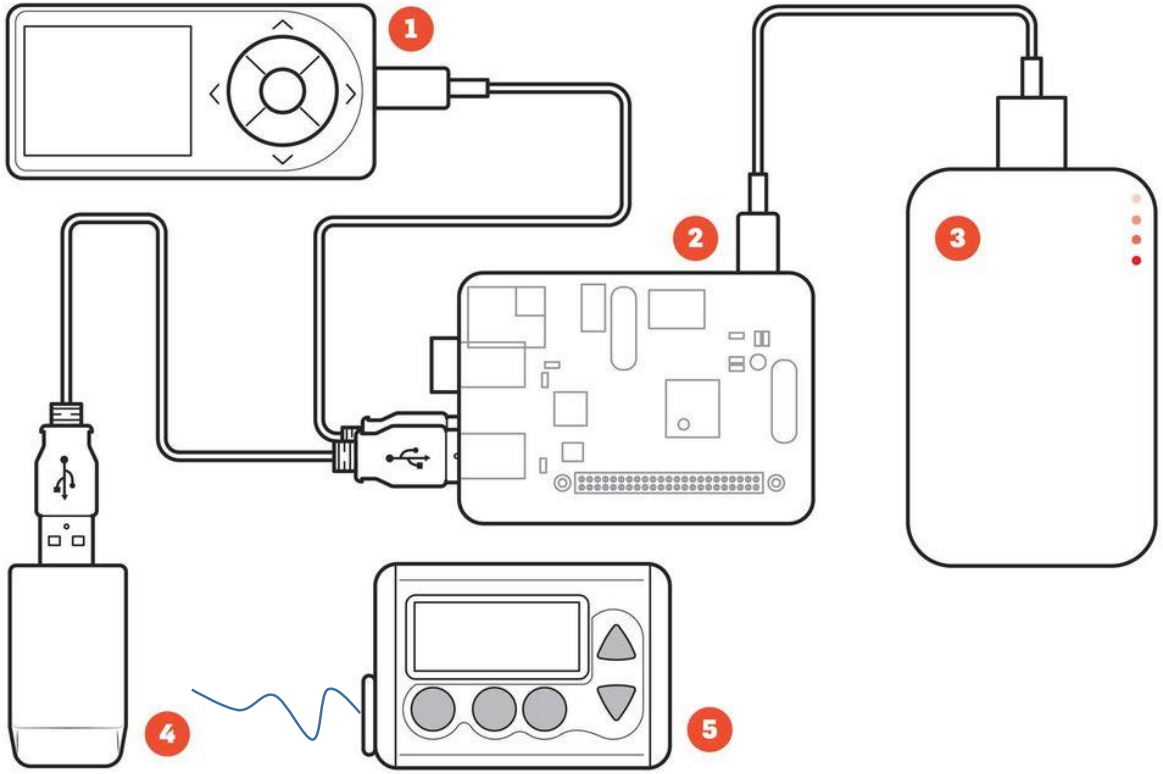
Components of an open source artificial pancreas



(Illustration by Clint Ford for Popular Science)

1. **Continuous glucose monitor**
2. Computer (“controller”)
3. Battery
4. Radio stick (“translator”)
5. **Insulin pump**

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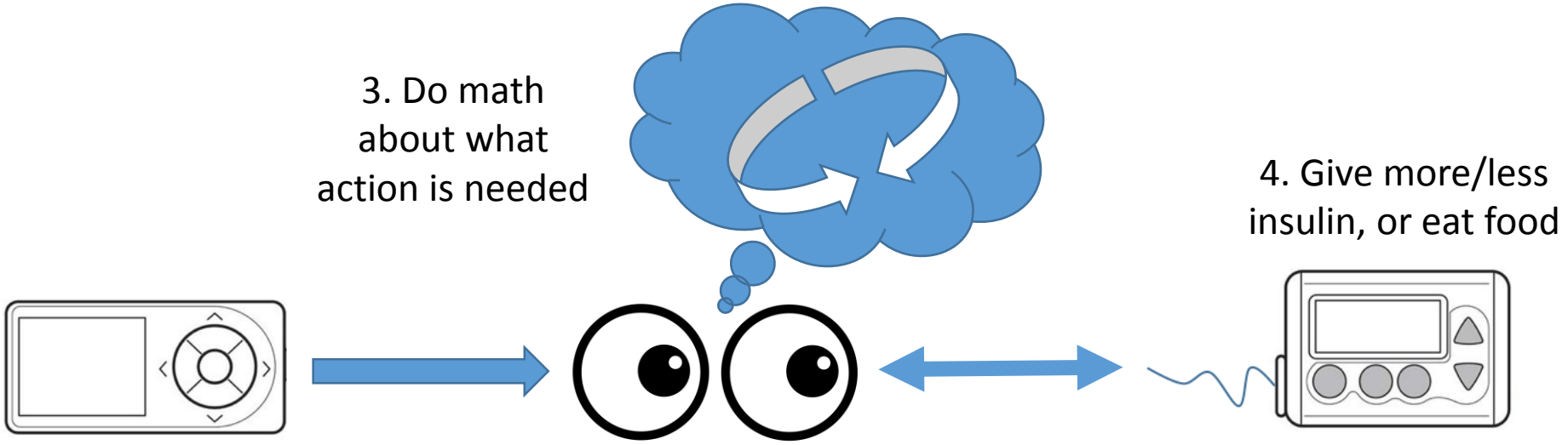
Manual diabetes:



5. Do it again.. and again... and again...

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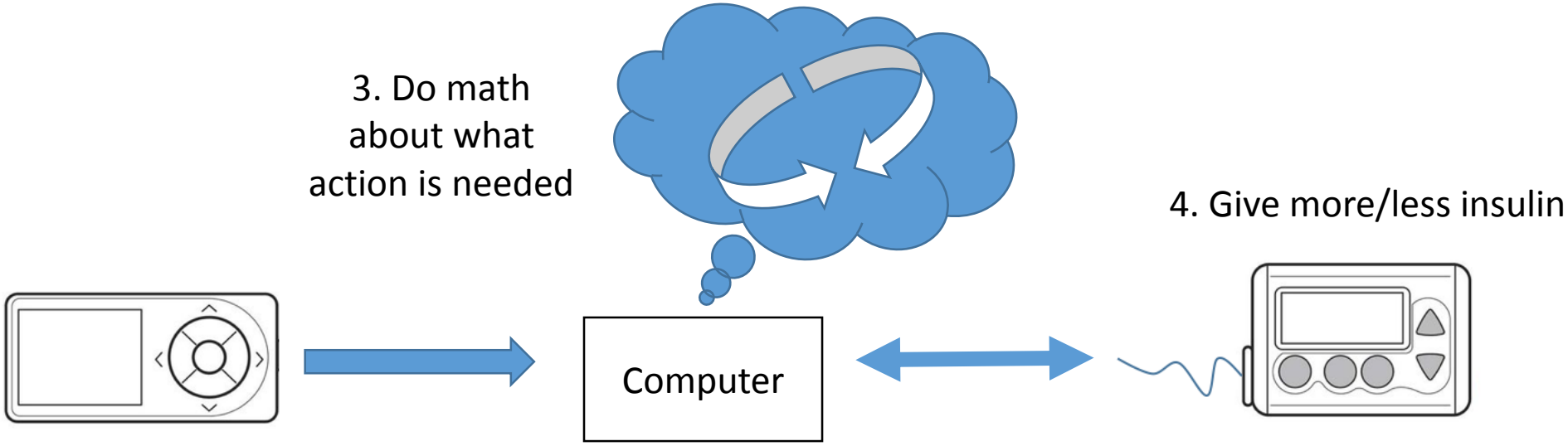
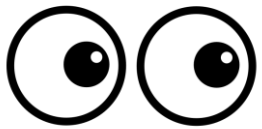
Automated diabetes:



5. Do it again.. and again... and again...



(human doesn't have to pay constant attention, but still checks in from time to time)

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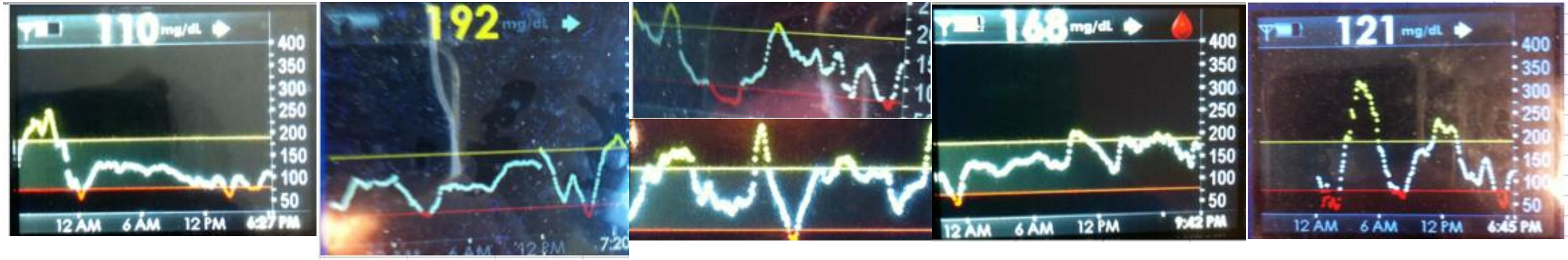
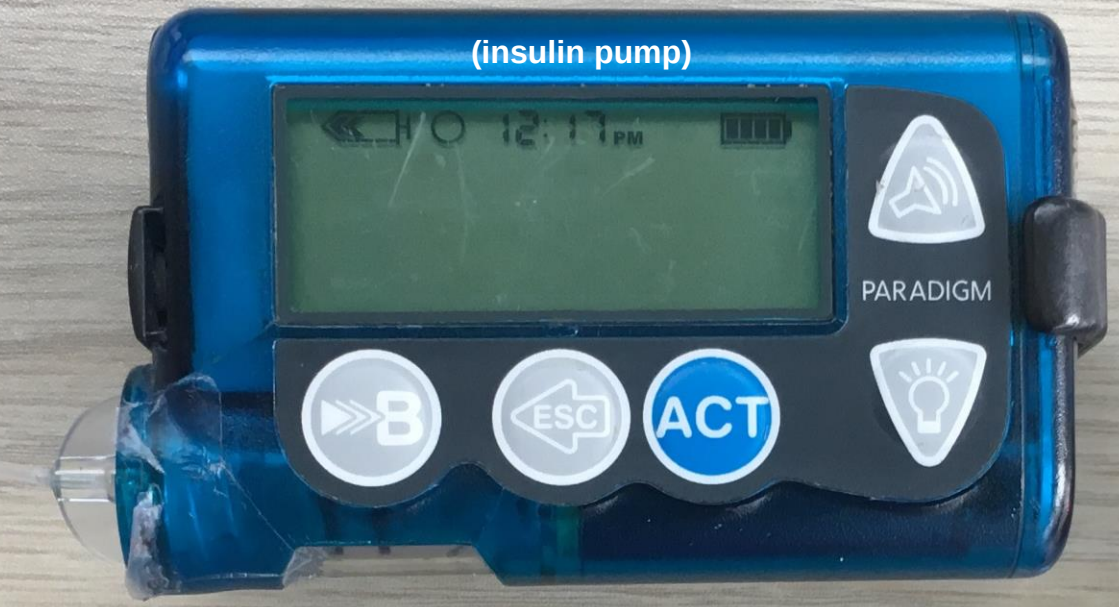
Before:

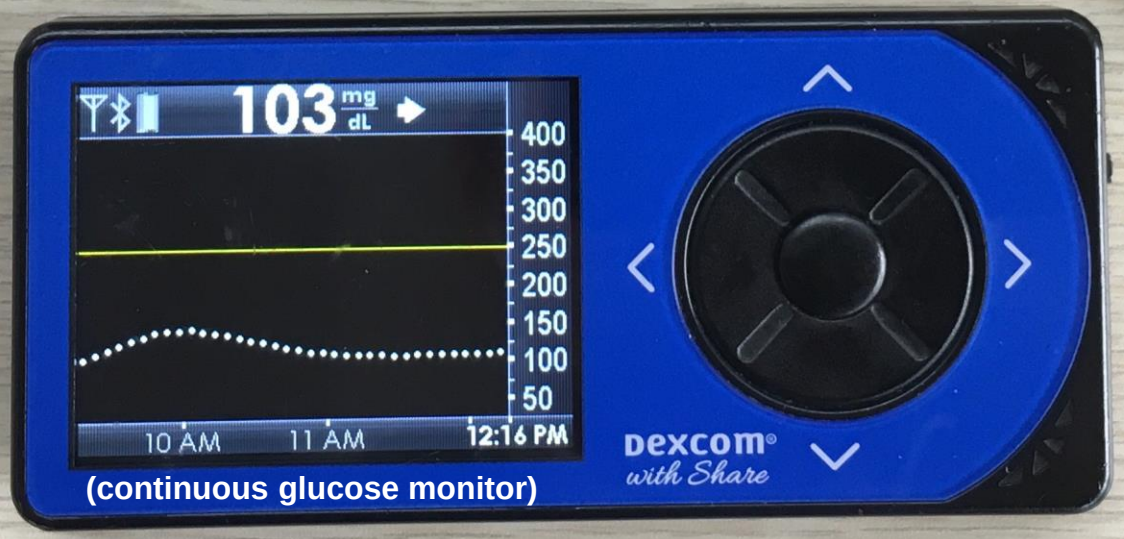


After:

(insulin pump)



OpenAPS “rig”



(continuous glucose monitor)

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www.OpenAPS.org

Do-It-Yourself (DIY)

Building, making, or combining disparate tools into a solution that works for yourself.

Often done when no commercial solution exists; or commercial solutions are not accessible; or because commercial solutions are not good enough to meet the needs of the individual.

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#OpenAPS

is an open and transparent effort to make safe and effective basic Artificial Pancreas System (APS) technology widely available to reduce the burden of Type 1 diabetes.

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#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

Reference design, code, documentation at OpenAPS.org

There are now (n=1)*916+ people with DIY closed loops in the world.

(That's something like

7,000,000+

hours of DIY closed loop experience.)

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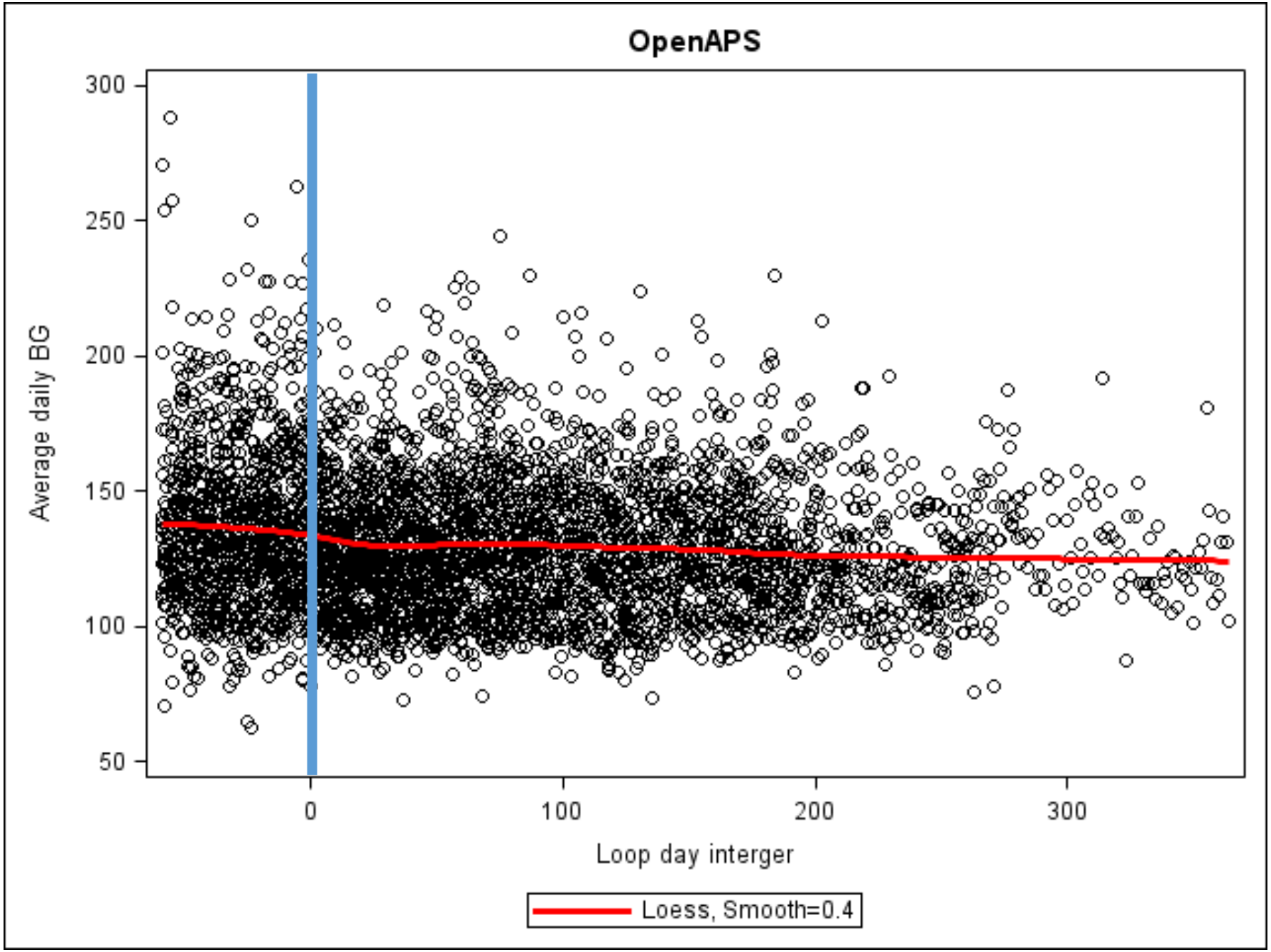

Sustained improvements in average BG

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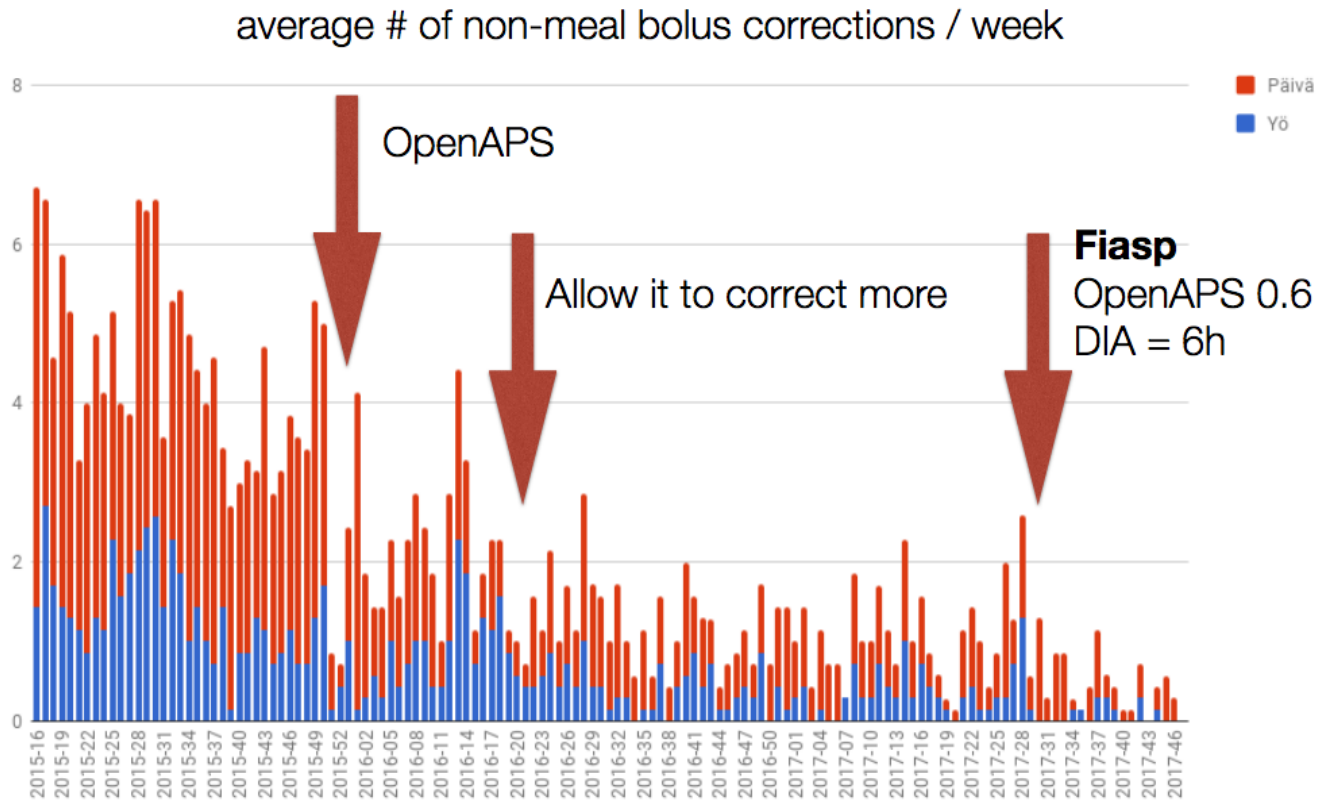
@sulka script assessing changes in treatments

https://github.com/sulkaharo/oref0-tools

Pre-OpenAPS:
4.5 manual interventions/ day



2018:
0.7 manual interventions/ day (85% reduction)

@DanaMLewis #2018ADA

@jbwittmer on QOL improvements of #OpenAPS:

- Annual School Nurse visits
  - 4th grade - before OpenAPS -- **420 visits** (2.3/day)
    - 354 “routine” visits for pre-lunch or pre-gym checks and decisions
    - 66 visits for hypo- or hyper-glycemic events
  - 6th grade - with OpenAPS – **5 visits** (0.027/day)
    - 3 gym-class associated hypoglycemic events
    - 2 equipment malfunction (CGM/OpenAPS rig)

Not traditional..

- Engineers
- Programmers
- Scientists
- Researchers
- Rocket Scientists

But yet we are:

- Engineers
- Developers
- Scientists
- Researchers
- Inventors

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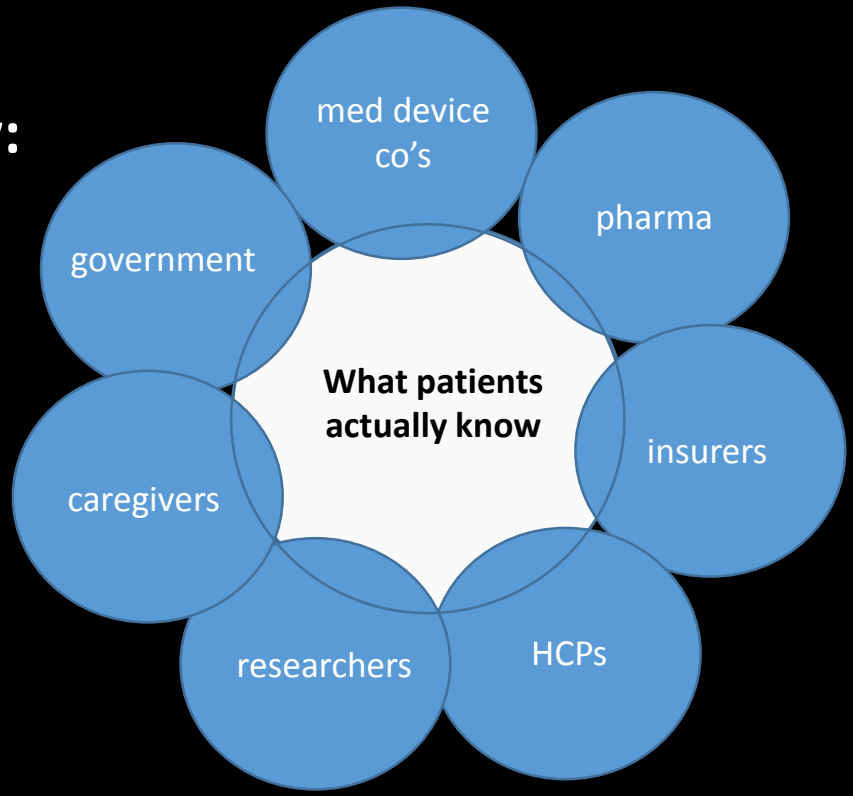
(Me, anytime someone says “but you’re not a _____”.)
Flickr: @gumuz
@DanaMLewis

Make sure patient-centered research is actually patient-centered

1. Involve patients at every step – from design to contextualizing results appropriately.
2. Don't fall into the imposter syndrome/patient syndrome trap:

Imposter syndrome:

What people think patients know:



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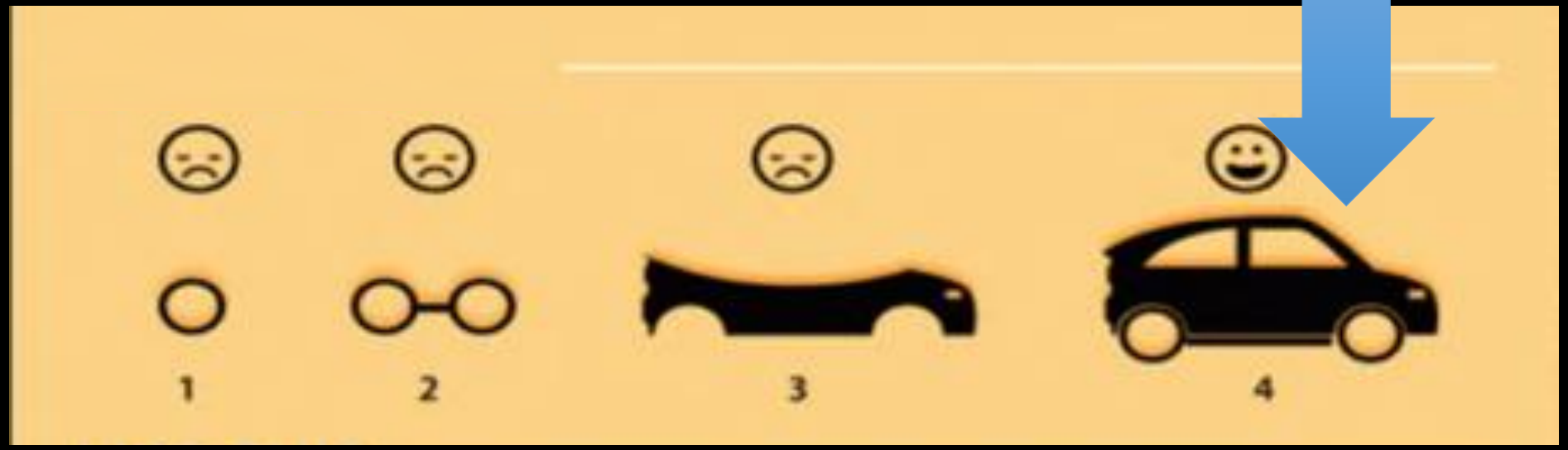
Traditional innovation



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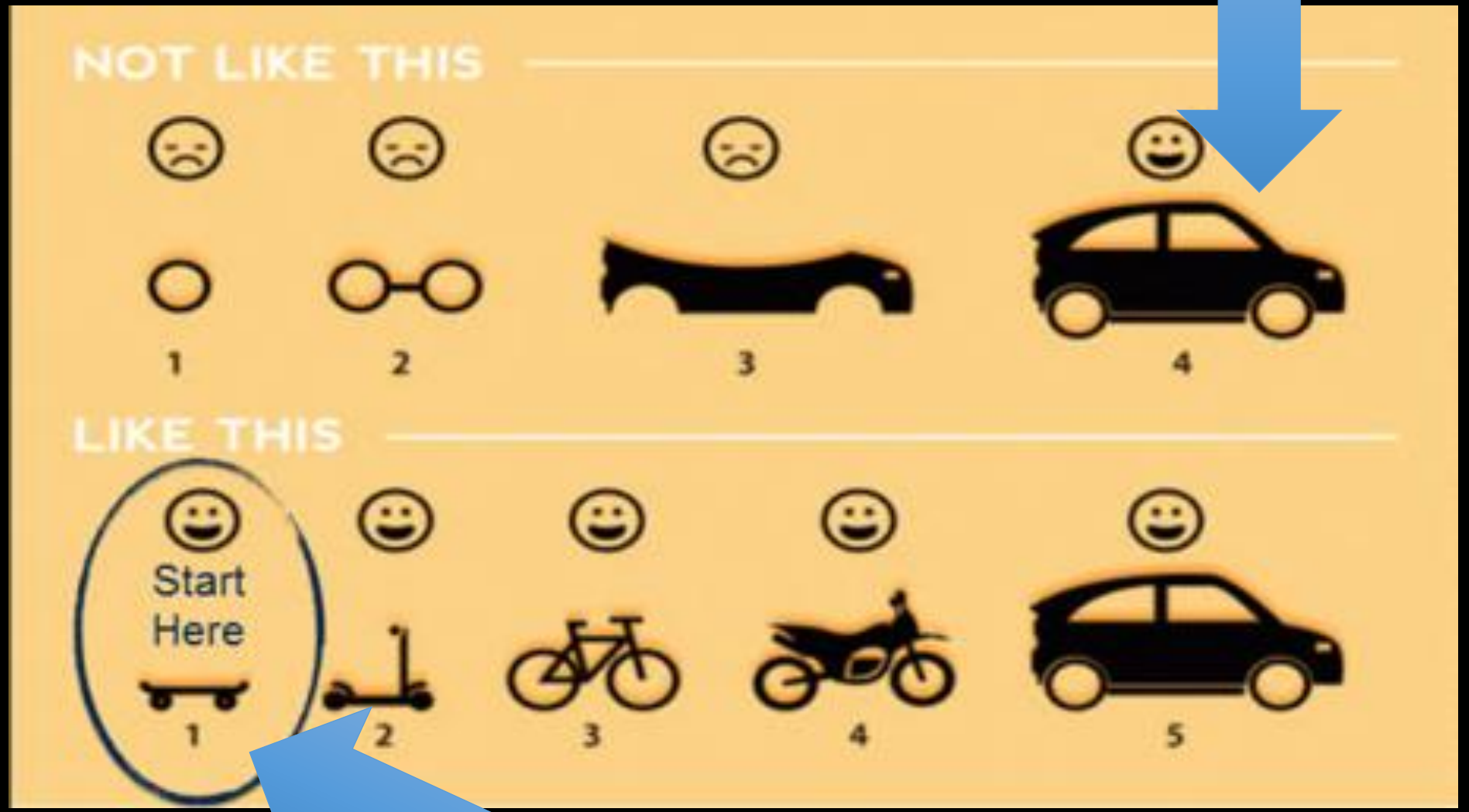
How companies approach solutions:



How patients approach solutions

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How might the world change if we leverage these collective innovations that happen every day?

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What happens when we enable patients to prioritize what we research and design solutions around?

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What happens when we surface and share data openly so anyone – regardless of "role" or credentials – **can use it to improve things?**

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What if we all say
#WeAreNotWaiting
to change the world like this?

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#WeAreNotWaiting

to change the future of healthcare.
But we can do it faster, together.

Will you help us?