SUPERPATIENTS
Patients who extended science when all other options were gone

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Society for Participatory Medicine
Bringing together e-patients and health care professionals.
@HelenBevan, NHS
(We’re activists)
How I came to be here

- High tech marketing: data geek; tech trends; automation
- 2007: Cancer discovery & recovery
- 2008: E-patient blogger
- 2009: Participatory Medicine, public speaking
- 2010: Full time
- 2011: international
- 2012: med schools, advisory, consult
- 600+ events, 19 countries, 1400 blog posts, 11 universities, 19 articles, 2 book chapters
It is the thesis of this presentation that as wonderful as modern medicine has become, further progress in care and self-care is being held back by a fundamental conceptual error about what “patient” means and its potential.
In other words, our “paradigm of patient” has become obsolete.
In short: our paradigm of patient is broken, and it’s holding back progress.
2007: My “Incidental Finding”
Routine shoulder x-ray, Jan. 2, 2007

“Your shoulder will be fine ... but there's something in your lung”
Classic Stage IV, Grade 4 Renal Cell Carcinoma

Illustration on the drug company’s web site

Median Survival: 24 weeks
“My doctor prescribed ACOR”
(Community of my patient peers)
My patient peers told me:

- This is an uncommon disease – get to a hospital that does a lot of cases
- There’s no cure, but HDIL-2 sometimes works.
  - When it does, about half the time it’s permanent
  - The side effects are severe.
- Don’t let them give you anything else first
- Here are four doctors in your area who do it
My patient peers told me:

• This is an uncommon disease – get to a hospital that does a lot of cases

• There’s no cure, but HDIL-2 sometimes works.
  • When it does, about half the time it’s permanent
  • The side effects are severe.

• Don’t let them give you anything else first

• Here are four doctors in your area who do it
Surgery & Interleukin worked

Baseline: 39x43 mm

50 weeks: 20x12 mm
ACOR’s practical information may have saved my life

As a responsible engaged patient, knowing that IL-2’s side effects might kill me, I sought to prepare myself. First I sought authoritative sources; there I found dry facts: “Side effects are often severe and rarely fatal, and include . . .” I thought, “What am I supposed to do with that?” and turned to my peers on ACOR. I asked, “You who’ve done this—what was it like? What do I need to know?” From them I received 17 firsthand stories—a wide range of experiences. I felt prepared—and today Dr McDermott says, “You were really sick. I don’t know if you could have tolerated enough medicine if you hadn’t been so well prepared.” In this case valuable—as in potentially lifesaving—information came from outside the establishment.
How can it be that the most useful and relevant and up-to-the-minute information can exist outside of traditional channels?
Answer: Knowledge is power, and access has changed forever
Because of the Web, Patients Can Connect to Information and Each Other (and other Providers)
“Information capillaries”
Also:
Information liquidity transforms what’s possible
Not liquid: coffee beans

Flickr user wuestenigel
Liquid: cup of coffee

Kerena Reese, Cosmofunnel.com
Not liquid

- Slow and predictable
- Moving it takes effort
- Unexpected arrivals are highly suspect

Liquid

- Fast and unpredictable
- *Controlling* it takes effort
- Unexpected arrivals are no surprise
Knowledge
(including data)
truly is power.
Empowerment

“Increasing the capacity of individuals or groups to make choices [about what they want] and to transform those choices into desired actions & outcomes”

World Bank, 2002
It’s perverse
to keep someone uninformed
then say “They seem ignorant!”
Let’s meet just a few of the Superpatients
OpenAPS creators at #2016ADA: the story, the status, the poster
Welcome to Nightscout

What is the Nightscout project?

Welcome to the Nightscout Project

Connect with:

Search ...

Disclaimer

All information, thought, and code described here is intended for informational and
#DIYPS
(“Do-it-yourself Pancreas System”)

@DanaMLewis | #DIYPS
#DIYPS: Open Source pancreas!
(“Do-it-yourself Pancreas System”)

Here’s what a closed loop #DIYPS artificial pancreas looks like:
#OpenAPS users are tweeting

Matthias @ceben80 · Aug 31
A fantastic flatline thanks #OpenAPS my xDrip statistics reports a A1C of 4.9% of this night, yeah
As of October 20, 2018, there are more than \((n=1)\times 951+\text{ individuals}\) around the world with various types of DIY closed loop implementations (that we know of). This number continues to grow, as does the number of options for various types of DIY closed loops!

We currently estimate this collective DIY community has more than 7,300,000+ real-world “loop hours”. (This rough calculation for estimating loop hours is based on approximately 8 hours per 24 hour period for someone who uses the system overnight; and 20 hours per 24 hour period for someone who may use the system 24/7, to account for any downtime.)

This means #OpenAPS and other DIY closed loop users experience fewer highs, less severe lows, and more “time in range”: most users self-report less of both highs and lows, plus more time in range, AND hbA1c reductions – not to mention the quality of life improvements associated with
Superpatients: Kristina Sheridan and daughter Kate
Kate Sheridan – nasty Lyme case

- 30 doctors
- 15 diagnoses
- From star student & athlete to unable to read a single page
• “Printouts over a foot high ... typed it into Excel.
• “We took her lab data, her medication treatment timelines... But there was more to it. She had 26 symptoms.
• “We started tracking their severity. Our spreadsheet had not just clinical data but her patient data.
• “We also added for each of those trials how she’d responded.”
Kate’s view

• “I can’t tell you how powerful it is to be able to hold that journey in my hands.

• “There are many patients out there who have far crazier stories ...but who do not have the tools to share them. I am asking you to help us change that.”
Superpatient: Michael Morris

- Stage IV colorectal (mets to liver, lungs)
- Four hospitals; unable to coordinate information

Problem

Patient Data is Siloed across multiple EHR and other systems (conditions, treatments, scans, genomics etc).

Protocol Treatments, Minimal Options for Patients. Patients spend an avg of 10 minutes with their doctor per visit. Difficult to come up with personalized treatment plan. Protocol is usually prescribed

Reactive “Call me if you get sick”. Lack of proactive patient monitoring. If issues arise, patients often call into their doctors or call their doctors office to be seen. EFs (emergency flys)
Michael Morris - Stage @CureSoft with FHIR

“I’m using my data across multiple hospitals to put together an integrated solution to manage my care with my care team.”
Cognitive dissonance sets in, and the mind seeks to resolve it:

“It’s because they’re college graduates.”
Science didn't understand my kids' rare disease until I decided to study it.
Patients and their advocates are getting an ever-larger voice in how medical research is carried out. They participate in the design of experiments and have a greater say in what outcomes they care about most — and it's not always simply living longer.

Sharon Terry has lived through a couple of decades during which patients went from being complete outsiders to participants. She worries now that they risk being co-opted by the medical research juggernaut.

Her story started in Boston in the mid-1990s, when she discovered that her two young children had been born with a rare genetic disease called pseudoxanthoma elasticum. It's a progressive disorder that causes connective tissue to gradually get hard, and can impair, skin, eyes and blood vessels.

"Researchers came and took blood from us and our kids," Terry says.

A few days later, another set of researchers wanted to take blood, too.

"We didn’t understand why they weren't sharing. And we also didn't understand why they weren't working together," she says.

Terry, who is now 60 and lives in Washington, D.C., was a college chaplain before the diagnosis. She founded a patient advocacy group called Genetic Alliance after her children were diagnosed with a rare disorder.
“Undocumented”

Superpatient: @Doug_Lind_Say
Meet Kim Goodsell

PO01-200 - LMNA-Mediated Arrhythmogenic Right Ventricular Cardiomyopathy and Charcot-Marie Tooth Type 2B1: A Patient-Discovered Unifying Diagnosis

May 7, 2014, 6:00 - 7:30 PM
Poster Town, Exhibit Hall

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Disclosures
J.J. Liang: Nor Scientific Corp.,

Abstract
Introduction: In genes encod envelope prote type 2B1, another laminopathy-associated condition, has not been described in the same patient.

Methods: N/A
15 year old
Superpatient: @JackAndraka
New pancan test
28x faster
26,000x cheaper
100x more sensitive
Winning the Intel international science & engineering fair
Seven more stories – Susannah Meadows (journalist)

The Other Side of Impossible: Ordinary People Who Faced Daunting Medical Challenges and Refused to Give Up

Hardcover – May 2, 2017
by Susannah Meadows (Author)

You’re faced with a difficult health condition. You have exhausted medicine’s answers. What do you do? Susannah Meadows tells the real-life stories of seven families who persisted when traditional medicine alone wasn’t enough.
If all these are true (and they are), how can we justify keeping patients away from their data and telling them to stop googling?
A common objection:

“OK, Dave, you’re like that, but the patients I know aren’t asking for this.”
This has strong parallels with what men used to think about women.
Vote **NO** on Woman Suffrage

BECAUSE 90% of the women either do not want it, or do not care.

their husbands' votes.

BECAUSE it can be of no benefit commensurate with the additional expense involved.

BECAUSE in some States more voting women than voting men will place the Government under petticoat rule.

BECAUSE it is unwise to risk the good we already have for the evil which may occur.

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National Association **OPPOSED** to Woman Suffrage

Headquarters
258 Madison Avenue
New York, N. Y.

Branch
726 Fourteenth Street, N. W.
Washington, D. C.

Votes of Women can accomplish no more than votes of Men. Why waste time, energy and money, without result?
That’s clearly a mental error.
April 1967 (fifty years ago): “K. Switzer” runs the Boston Marathon

“Get the hell out of my race!”
Remove constraints & what’s possible changes

1967  1972  2017

_TIT_ILE IX
_Sports Illustrated_

“*No person in the United States shall, on the basis of sex, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any education program or activity receiving Federal financial assistance....*”

—JUNE 23, 1972
Paradigm errors ➔ wrong expectations

1967  1972  2017

"No person in the United States shall, on the basis of sex, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any education program or activity receiving Federal financial assistance...."

—JUNE 23, 1972
Don’t make that mistake.
It is the thesis of this presentation that as wonderful as modern medicine has become, further progress in care and self-care is being held back by a fundamental conceptual error about what “patient” means and its potential.
For the future of health and care to achieve this, we must fix the paradigm.
“A new scientific truth does not triumph by convincing its opponents and making them see the light,
Max Planck  Nobel Prize, 1918

“A new scientific truth does not triumph by convincing its opponents and making them see the light, but rather because its opponents eventually die,
Max Planck  Nobel Prize, 1918  

“A new scientific truth does not triumph by convincing its opponents and making them see the light, but rather because its opponents eventually die, and a new generation grows up that is familiar with it.”
SUPERPATIENTS

Patients who extended science when all other options were gone

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