Let Patients Help Improve the Future of Care

Dave deBronkart
Twitter: @ePatientDave
dave@epatientdave.com
Fundamental principle for thinkers at this conference

If you live long enough, things change.

So don’t be surprised if new things are possible!
1871: Oliver Wendell Holmes

“Your patient has no more right to all the truth you know than he has to all the medicine in your saddle-bags.

He should get only just so much as is good for him.”

Bellevue graduation speech
Informatics pioneer
Dr. Warner Slack, since the 1970s

“Patients are the most underused resource in healthcare”
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, 20 countries, 1400 blog posts, 13 universities, 19 articles, 2 book chapters
Doc Tom said, “e-Patients are Equipped, Engaged, Empowered, Enabled”
THE PATIENT OF THE FUTURE

Physicians suggest. Patients ignore. Technology alone won’t bring them together. But a new relationship just might...
20 PEOPLE WHO MAKE HEALTHCARE BETTER

The very essence of healthcare is to make a difference for good. At its core, this is an industry focused on making life better for people. That simplicity of mission establishes a shared grounding for the millions who work daily to deliver the best healthcare they can. In our annual HealthLeaders 20, we offer profiles of some who are doing just that. You can read long form versions of each of these profiles, and listen to audio interviews online by visiting www.healthleadersmedia.com/20people/.

THE UGLY TRUTH ABOUT COST
Atul Gawande, MD

The reaction to the story was astonishing to Gawande, but not just because so many people thought it was unfair. It was because the story drew national attention to a very real problem in healthcare reform. A health system that has been the poster child for reasons why healthcare reform is so important.

The reason for the story was the price of a drug called Temozolomide. Temozolomide is a chemotherapy drug used for the treatment of glioma, a type of brain tumor. The drug is expensive, costing around $120,000 per year. Gawande found that the price of the drug was not determined by the cost of research and development, but by the market value of the drug. This led to a discussion about the cost of healthcare and the need for reform.

REFERENCES:
Me? An indicator of the future??

- Who’s getting online:
  - 1989: Me (CompuServe sysop)
  - 2009: 83% of US adults (Pew)

- Who’s romancing online:
  - 1999: I met my wife (Match.com)
  - 2009: One in eight weddings in the U.S. met online
  - 2011: One in five couples met online
2007: My “Incidental Finding”
Routine shoulder x-ray, Jan. 2, 2007

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

Illustration on the drug company’s web site

Median Survival: 24 weeks
Facing death
My mother
My daughter
After the shock you’re left with the question:
What are my options?
What can I do?
“My doctor prescribed ACOR”  
(Community of my patient peers)
Surgery & Interleukin worked – in six months
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
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.
Social media: “information capillaries”
But how is this possible??

They don’t have the education!
But they do have motivation, and focus, and now they have access to knowledge (which is empowering)
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
Meet the Superpatients
Patients who extend science when all other options are gone
Superpatient: @DanaMLewis

with @ScottLeibrand and the whole
#OpenAPS #DIYPS #NightScout crowd
#WeAreNotWaiting
(to change the way we research and innovate in healthcare)

@DanaMLewis
#OpenAPS:
Better control than a working pancreas
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

Authors
Jackson J. Liang, DO, Kim Goodsell, No Degree, Martha Grogan, MD and Michael J. Ackerman, MD, PhD. Mayo Clinic, Rochester, MN

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

Methods: N/A
Superpatients: Kristina Sheridan and daughter Kate
Kate Sheridan – nasty Lyme case

• 30 doctors
• 15 diagnoses
• From star student 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: Total Symptom Load
Michael Morris - Stage IV colorectal (liver, lungs)

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 too late and end up in expensive ER visits.
Michael Morris - Stage IV
@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.”
THE PATIENT INNOVATOR TRACK

November 20, 2019

A new phenomenon at DevDays is the Patient Innovator Track. This track celebrates patient engagement through innovation. Patients are central to healthcare, and their voice needs to be heard. The Patient Innovator Track aims to bring together patients, developers, and healthcare providers to discuss how technology can improve patient care and experiences.
Latest Solutions

Girls develop app to help detect fake drugs

AUTS

Blind woman develops several technologies to help the blind

Mother builds device to help prevent children from dying in hot cars

LoveRose Lingerie

Patient who struggles with depression builds app to help him cope with this condition
Empowerment

“An empowering approach to participation treats poor people as co-producers with authority and control over decisions and resources devolved to the lowest appropriate level.”
Empowerment

“An empowering approach to participation treats patients as co-producers with authority and control over decisions and resources devolved to the lowest appropriate level.”
THAT is a paradigm change for patient experience, empowerment, and engagement.
People will tell you this is crazy.
If you live long enough, things change.
1871: Oliver Wendell Holmes

“Your patient has no more right to all the truth you know than he has to all the medicine in your saddle-bags. He should get only just so much as is good for him.”

Bellevue graduation speech
“I by no means expect to convince experienced naturalists whose minds are stocked with a multitude of facts. . . .

[B]ut I look with confidence to the future,—to young and rising naturalists, who will be able to view both sides of the question with impartiality.”
“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.”

Max Planck  Nobel Prize, 1918
Enable achievement by the person in trouble.
Let Patients Help Improve the Future of Care

Dave deBronkard
Twitter: @ePatientDave
dave@epatientdave.com