"e-Patient Dave" deBronkart
Patient (kidney cancer 2007; pre-diabetes)
S.B. MIT, 1972
Blogger, author, healthcare keynote speaker, health policy advisor
E-Patient Dave, LLC; Society for Participatory Medicine
Nashua NH

How I came to be here
- High tech: marketing, data geek, change agent
- 2007: Cancer discovery & recovery
- 2009: Health IT, Participatory Medicine, public speaker
- 2010: full time
- 2011: international; TED Talk
- 2014: “elevated A1c”

Fundamental law: If you live long enough, things change
Corollary: Don’t be surprised if things aren’t the way they used to be.
Corollary: Don’t expect things to stay this way, either.

Also 1969: Citizen Participation (Sherry Arnstein)

1871: Oliver Wendell Holmes

“Your patient has no more right to all the truth 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

1946

1973

“We didn’t have the information we needed, so we decided to find it on our own.”

(Sound a bit like #WeAreNotWaiting?)
1978: Tom Ferguson MD

1994: “Doc Tom”

2001: AMA new year letter

2007: My “Incidental Finding”

Doc Tom said, “e-Patients are Equipped Engaged Empowered Enabled”
Stage IV, Grade 4 Renal Cell Carcinoma

Because of the Web, Patients Can Connect to Information and Each Other

Surgery & Interleukin worked

Paternalistic caring

“No, honey – you don’t know what you need.”

“I’ll take care of you.”

“I’ll decide for you.”

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

When does autonomy become appropriate?
What do we mean by Engaged? Participating?

1969: Citizen Participation (Sherry Arnstein)

Levels of Public Participation

http://www.openscientist.org/2013/01/the-levels-of-citizen-science.html

http://staff.maxwell.syr.edu/cgerard/Fundamentals%20of%20Conflict%20Resolution/Slideshows/Public%20Policy%20Conflict.ppt
Citizen Participation

What makes it possible for the powerless to create meaningful results?

In other words, what do we mean by Empowered?

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

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.”

Transformation of Knowledge Access

Notice that valuable insights from other disciplines are now altering what’s possible in health and care

It's no longer all about the biology.

DIKW Collaboration Model

Collective wisdom is enabled to be greater than – and transformed from – individual wisdom as “information nutrients” and peer-to-peer discovery spread
Each is driven by a shift in information pathways, newly empowering autonomy

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

I know: Gadgets!!

Withings Wi-Fi scale
Fitness wristband & heart band

YMCA Diabetes Prevention Class (food training & physical activity)
MyFitnessPal diet tracking app
Strong support from my spouse

p.s.: My providers can't see this in their computers!

OMG, I'm a runner now
But then:

Nov 2014, 231#: 5.8
Sept 2015, 203#: 5.9 (???)
August 5, 2016:
• Labcorp: 5.7
• Quest: 5.5

HbArg!

Do any of us now think “That’ll never happen?”

“Quantified Self”
Public Health conference

How might we *encourage* that future?

What information will PRE diabetics discover, on their own, that helps them avoid Type 2?

It takes enlightened educators to alter our cultural expectations at scale…and teach it to others.
Culture change alters what’s possible.

It involves altering people’s beliefs about what is appropriate behavior.

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<table>
<thead>
<tr>
<th>TABLE 5.2 Characteristics of a Continuously Learning Health Care System and Environment</th>
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<tbody>
<tr>
<td><strong>Science and Information</strong></td>
</tr>
<tr>
<td>Frequent access to knowledge—A learning health care system contains cognitive, context, and decision-making tools to guide expenditure, clinical decision-making, and care quality.</td>
</tr>
<tr>
<td><strong>Patient-Clinician Partnerships</strong></td>
</tr>
<tr>
<td>Engaged, empowered patients—A learning health care system is anchored on patient needs and perspectives and promotes the inclusion of patients, families, and other caregivers as vital members of the continuously learning care team.</td>
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</tbody>
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When does autonomy become feasible?

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If you live long enough, things change.

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Educator takeaways

1. Key drivers of these changes:
   - New patterns of knowledge transfer
   - New technology enabling "situational awareness"
   - The beginnings of the great patient awakening

2. Key obstacles:
   - Lack of awareness that patient power is feasible
   - Disbelief (among all parties)
   - Too often it's really hard to do the right thing (for no good reason!)

3. Available educator actions (1)
   - Make it easier to do the right thing.
     - Speak truth to power about this.
     - “Careful & kind care”
   - Fight for integration of behavioral/mental health into primary care

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,"

3. Available educator actions (2)
   - “Usability”: ask “Would it make sense to ask this person to do this set of tasks at their job?”
   - As appropriate, help each patient understand the above and encourage them to be empowered.
   - Collect your own observations and stories of how this plays out and what the obstacles are.
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.”

When new things become possible, best practices change.

Stewart Brand  
*Publisher of the Whole Earth Catalog*

“This is Spinal Tap”  
*A poster for the film*
This is Culture Change