

Patients of the Future: Patient-Clinician Partnerships

E-Patients, Patient Engagement and Participatory Medicine

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Beyond Empowerment: Patients, Paradigms, and Social Movements

What will **YOU** do to change the world?

Simulation Techniques for Teaching Time-Outs
Statewide Initiative to Prevent Workplace Violence
Medication Errors in Surgery



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: TED Talk, international, IKF!
 - 2012: med schools, advisory, consult
 - 650 events, 26 countries, 1500 blog posts, 13 universities, 19 articles, 2 book chapters



**Fundamental principle 1:
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

*Informatics pioneer
Dr. Warner Slack,
since the 1970s*

**"Patients are
the most under-
used resource
in healthcare"**



**Fundamental principle 2:
When assets digitise,
things change fast.**

**Fundamental principle 3:
Patients are the
ultimate stakeholder.**



e-patients.net
because health professionals can't do it alone

Doc Tom said,
"e-Patients are **Equipped
Engaged
Empowered
Enabled**"



Society for Participatory Medicine
Bringing together e-patients and health care professionals.



HealthLeaders
SEPTEMBER 2009

THE PATIENT OF THE FUTURE
Physicians suggest. Patients ignore. Technology alone **can't** a new relationship just might.

COVER STORY
16 The Patient of the Future

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The Engaged Patient
12 items in my pre-appointment "agenda" email

Ophthalmic migraine?

- Shape of the disturbance is exactly as shown at right (from <http://www.schmidwende.com/simulation.asp?migraine1>)
- But the interior is dazzling, not the pattern shown here.
- Behavior is as described at that site and others (see log below)
- The shape may point left or right.

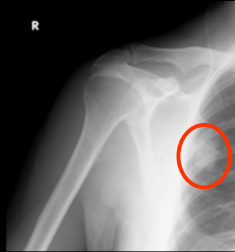
#	Date	start	approx	gone by	Notes
1	30-Oct				
2	4-Nov	8:58		9:22	Wife's 60th birthday
3	21-Nov	12:35		12:50+	Long gone by 1:30. Different shape this time - almost a mirror of the other, right of center, below center. Note: Thanksgiving was 11/23. The usual Nike-like chevron. Note: with both eyes closed it's like yellow & black stripes. Start: non-specific sense of daze.
4	25-Nov	19:40			
5	6-Dec	12:05		before 12:50	

Shoulder

- Range of motion complaint: "right shoulder is having range of motion trouble. No discomfort, but it just doesn't seem to work right: I find myself lifting my shoulder instead of the arm."
- Made a Jan 2 appointment w/ Dr Zilberfab

2007: My "Incidental Finding"

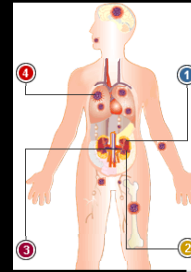
Routine shoulder x-ray, Jan. 2, 2007



"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

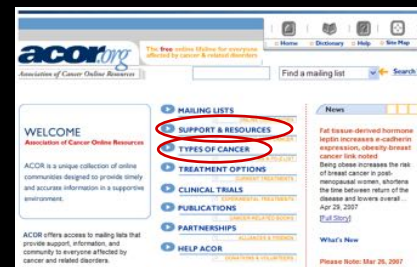


**Median Survival:
24 weeks**

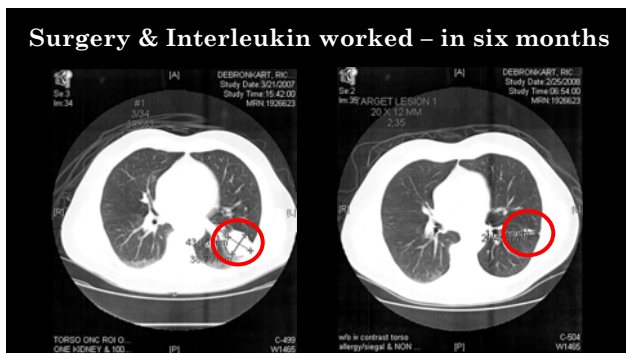
After the shock
you're left with the question:
What are my options?
What can I do?

"My doctor prescribed ACOR"

(Community of my patient peers)



Surgery & Interleukin worked – in six months



BMJ

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



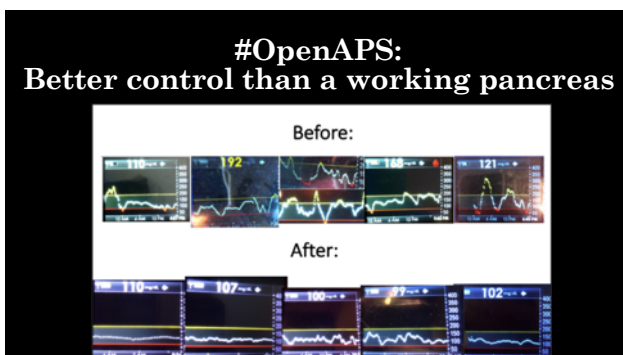
Social media: “information capillaries”



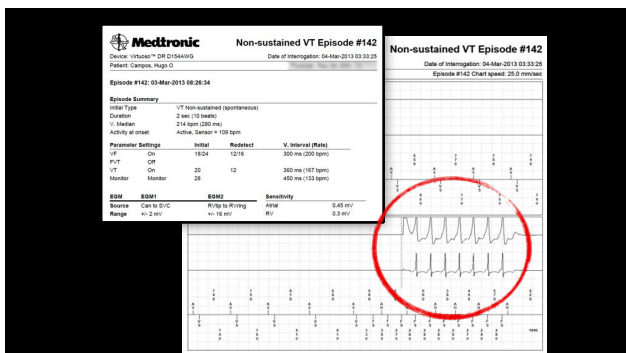
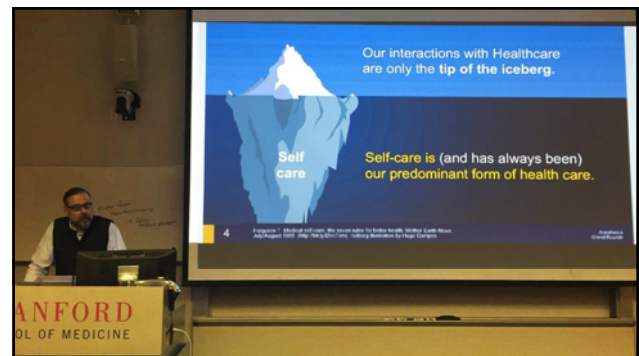
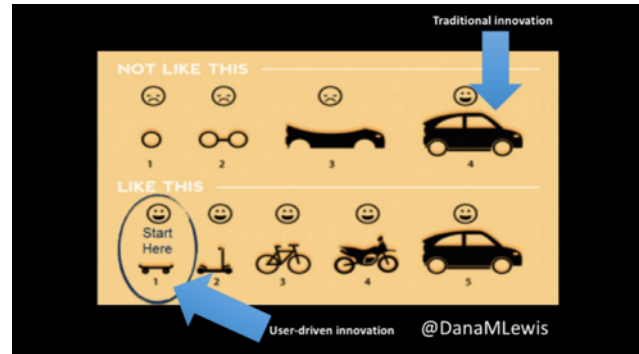
But how is this possible??
They don't have the
education!

But they do have motivation,
and focus,
and now they have
access to knowledge
(which is empowering)

Let's meet some
highly activated
chronic
e-patients of today.



#OpenAPS users are tweeting



Let us see
if we can give
the citizen in need
the power, authority,
and support
to help themselves ...
as *they* define it.

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

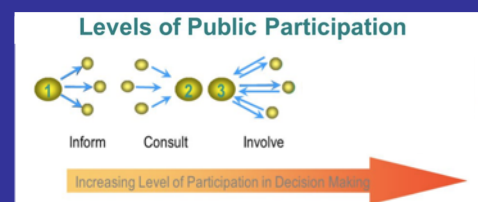
“An empowering approach to
participation treats poor people
as co-producers
with authority and control
over decisions and resources
devolved to the lowest
appropriate level.”

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.”

THAT
is a paradigm change
for patient experience,
empowerment,
and engagement.

Citizen Participation level 3: Involving the public in your work



<http://staff.maxwell.syr.edu/gerrard/Fundamentals%20of%20Conflict%20Resolution/Slideshow/Public%20Policy%20Conflict.ppt>

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Example of what a difference “consult” makes: here’s a sidewalk created before consulting the citizens. See next slide.

As gorgeously designed

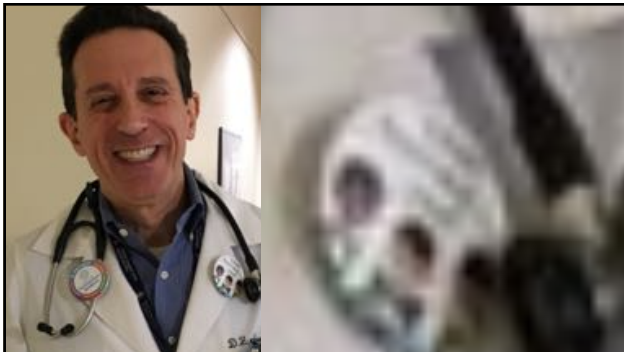
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What they would have asked for if they'd been consulted (Design thinkers call this “desire lines”)

As gorgeously designed

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My magic incantation:

“I’m the kind of patient who likes to understand as much as I can.”

“Do you mind if I ask questions?”

