Putting Patients at the Heart of the Clinical Trial

How I came to be here

- High tech marketing
- Tech trends; innovation; automation
- 2007: Cancer discovery and recovery
  - 2008: E-Patient blogger
  - 2009: Participatory Medicine, Public Speaker
  - 2010: full time
  - 2011: international

Foundation Principles

- Patient is not a third person word
  - Your time will come
- Patients are the ultimate stakeholder
  - Yet they’re often omitted from planning the future
- A pivotal force: The urge to care for our children and elders is strong.

Doc Tom said, “e-Patients are Equipped Engaged Empowered Enabled”
Me? An indicator of the future??

Who’s getting online:
- 1989: Me (CompuServe sysop)
- 2009: 76% 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

Who’s microwaving online:
- 2011: One in five couples met online

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

The Incidental Finding
Routine shoulder x-ray, Jan. 2, 2007

Multiple tumors in both lungs
Where’s This From?!

Primary Tumor: Kidney

Classic
Stage IV,
Grade 4
Renal Cell Carcinoma

Illustration on the drug company’s web site

Median Survival: 24 weeks
Facing the Reaper

My mother

My daughter

E-Patient Activity 2:
“My doctor prescribed ACOR”
(Community of my patient peers)

ACOR gave me:
• Information from people like me – Trust
• People who see the problems the way I do
• Practical information about side effects

Surgery & Interleukin worked.
Target Lesion 1 – Left Upper Lobe
How can it be that the most useful and relevant and up-to-the-minute information can exist outside of traditional channels?

Dr. Lindberg: 400 years

"If I read two journal articles every night, at the end of a year I’d be 400 years behind."

The lethal lag time: 2-5 years

The time it takes after successful research is completed before publication is completed and the article’s been read.

Because of the Web, Patients Can Connect to Information and Each Other (and other Providers)

Death by Googling: Not.

(Prof. Gunther Eysenbach, Europe: 9 deaths found in a three year search)

Compare with “To Err is Human” (98,000 deaths/yr Nov 1999)

“It may be more dangerous not to google your condition.”
“These conclusions are no more anti-doctor or anti-medicine than Copernicus and Galileo were anti-astronomer.”

Patients can simply contribute more today than in the past.

Thomas Goetz, Wired

Web 2.0: “When the web began to harness the intelligence of its users.” – Tim O’Reilly

Your Test Results

Your results are as follows: Question!

Test results are shown. Question!

Psoas muscle

(My kidney tumor was encroaching on it)

Same data – better software.

Information: clearer.

Consumer: informed, enabled.
Why not “Google Earth for my body”?

Who gets to say which outcomes are important??

Who gets to say which outcomes should be goals?

Who gets to declare which endpoint we measure?

Who gets to say which outcomes should be goals?

Who gets to say what’s in the patient’s best interest?
I predict a new battlefield: time versus certainty

To the scientist, the time when we find the truth is irrelevant to its worth.

But to a patient with a progressive disease, time is everything

Time Value of Money
“A dollar today is worth more than a dollar next year”

Patients are proposing there’s a Time Value of a Treatment
“A treatment today is worth more than the same treatment next year”
For patients with a progressive disease...

“A treatment today may be worth more than a better treatment next year”

What are the factors as a patient’s condition and development of a treatment progress in parallel?

Factors in the value equation

- **Efficacy**
  - We hope efficacy will improve as we continue developing the drug
- **Certainty** of the effect
  - More studies, and improvements in drug development, increase certainty (reduce p)
- **Patient’s need**, utility, benefit, etc

Time Value of a Treatment as time progresses:

\[ V_{tx,t} = f(\text{efficacy}_t, \text{certainty}_t, u_t) \]

The patient’s request:

“Engineer us some relief – NOW, please!

Time is of the essence.”

Trust: Have you asked patients what would make them feel protected?

Perry D. Cohen, Ph.D.
Management - Organization Behavior, Market Research at MIT Sloan School of Management
Now a Parkinson's patient
Developer of patient communities and research partnerships
Parkinson Pipeline Project
pdpipeline.org
Trust: Have you asked patients what would make them feel protected?

Paternalistic concern

“No, honey – you don’t understand – I’ll do that for you”
Thank you, medicine.

Please: Let Patients Help

“e-Patient Dave” deBronkart
Twitter: @ePatientDave
Facebook / ePatientDave
LinkedIn / ePatientDave
dave@epatientdave.com

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