Let Patients Help Heal Healthcare

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Society for Participatory Medicine
Bringing together e-patients and health care professionals.
How I came to be here

• High tech marketing
• Data geek; tech trends; automation
• 2007: Cancer discover & recovery
• 2008: E-Patient blogger
• 2009: Participatory Medicine, Public Speaker
• 2010: full time
• 2011: international
“It can be argued that the largest yet most neglected health care resource, worldwide, is the patient...”
Foundation Principles

• Patient is not a third person word
  – Your time will come
  – It’s a collective noun.

• 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
Doc Tom said, "e-Patients are Equipped, Engaged, Empowered, Enabled"
Society for Participatory Medicine

Bringing together e-patients and health care professionals.
Pt of future

Physicians suggest. Patients ignore. Technology alone won't bring them together. But a new relationship just might. p 16

Certifiable Stroke Care p 33
The Art of Balancing Risk p 47
Real-World Bundling p 53
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
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.richmondevie.com/simulation.asp#migraine](http://www.richmondevie.com/simulation.asp#migraine)).
- 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.

<table>
<thead>
<tr>
<th>#</th>
<th>Date</th>
<th>Start</th>
<th>Gone by</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>30-Oct</td>
<td>(approx)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>4-Nov</td>
<td>8:58</td>
<td>9:22</td>
<td>Wife's 60th birthday</td>
</tr>
<tr>
<td>3</td>
<td>21-Nov</td>
<td>12:35</td>
<td>12:50+</td>
<td>Different shape this time - almost a mirror of the other, right of center.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Note - Thanksgiving was 11/23</td>
</tr>
<tr>
<td>4</td>
<td>25-Nov</td>
<td>19:40</td>
<td></td>
<td>The usual Nike-like chevron. Note: with both eyes closed it’s like yellow &amp; black stripes.</td>
</tr>
<tr>
<td>5</td>
<td>6-Dec</td>
<td>12:05</td>
<td>before 12:50</td>
<td>Start: non-specific sense of dazzle;</td>
</tr>
</tbody>
</table>

**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 Zilberfarb
The Incidental Finding

Routine shoulder x-ray, Jan. 2, 2007

“Your shoulder will be fine ... but there’s something in your lung”
Multiple tumors in both lungs
Where’s This From??
Primary Tumor: Kidney
E-Patient Activity 1: 
Researching my condition

Renal Cell Cancer Treatment (PDQ®) - Stage IV and Recurrent Renal Cell Cancer

Stage IV renal cell cancer is defined by the following stage groupings:
- T4, N0, M0
- T4, N1, M0
- Any T, N2, M0
- Any T, any N, M1

The prognosis for any treated renal cell cancer patient with progressing, recurring, or relapsing disease is poor, regardless of cell type or stage. Almost all patients with stage IV renal cell cancer are incurable. The question and selection of further treatment depends on many factors, including prior treatment and site of recurrence as well as individual patient considerations. Carefully selected patients may benefit from surgical resection of localized metastatic disease, particularly if they have had a prolonged, disease-free interval since their primary therapy. Because of early reports of success, progestational agents have been administered to patients with metastatic renal cell cancer, but the response rates have been disappointingly low; therefore, no rationale exists for their use as single-agent therapy. Other therapies have been...
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
After the shock you’re left with the question:
What are my options?
What can I do?
Get engaged.
Get it in gear.
Do everything you can.
E-Patient Activity 2:
“My doctor prescribed ACOR”
(Community of my patient peers)
E-Patient Activity 3: Reading (and sharing) my hospital data online
E-Patient Activity 4:
My own social support network
(CaringBridge.org - family and friends - journal & guestbook)

Dave deBronkart

MY STORY

1/30/07:
On January 2 a routine shoulder x-ray showed a mass in a nearby part of my lung. Four weeks later, it appears to be kidney cancer that’s spread to both lungs. This site will chronicle the learning and emotional processes we’re going through as we learn and do everything we can to maximize my chances. Top of the list: a strong mental attitude and a clear mind!
E-Patient Activity 5:
Tracking my data

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chest x-rays and scans</strong></td>
<td></td>
<td>5-Jan</td>
<td>30-Jan</td>
<td>21-Mar</td>
<td>APRIL</td>
<td>14-May</td>
</tr>
<tr>
<td><strong>Target Lesions</strong></td>
<td>Slice</td>
<td>CT</td>
<td>MRI</td>
<td>CT</td>
<td>R</td>
<td>CT</td>
</tr>
<tr>
<td>Target #1 (left lower)</td>
<td>34-36, mid right</td>
<td>43x39</td>
<td>37x35</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Target #2 (right upper lobe)</td>
<td>23-24, lower left</td>
<td>41x33</td>
<td>42x32</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Target #3 (apex of right lung)</td>
<td>13, near trachea on left</td>
<td>24x22</td>
<td>14x11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Target #4 (Left upper anterior)</td>
<td>40, front of left lung</td>
<td>43x</td>
<td>20x13</td>
<td>24x14</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SCORE</strong></td>
<td></td>
<td><strong>38.18</strong></td>
<td></td>
<td><strong>31.29</strong></td>
<td>Reduction since March 07</td>
<td>18%</td>
</tr>
</tbody>
</table>
Surgery & Interleukin worked.

Target Lesion 1 – Left Upper Lobe

Baseline: 39x43 mm

50 weeks: 20x12 mm
Question:
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.”

It’s not humanly possible to keep up.
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.

During this time, people who might have benefitted can die.

Patients have all the time in the world to look for such things.
Because of the Web, Patients Can Connect to Information and Each Other (and other Providers)
Death by Googling: Not.

(Dr. Gunther Eysenbach, Europe: 0 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.
“How can patients participate if they can’t see what I see?” – Dr. Danny Sands
Lesson learned: People perform better when they’re informed better.
Obstacle to adoption:

“Patients will flood us with time-wasting questions.”
What happens when patients see their doctors’ notes?
“OpenNotes” project begins: what happens when patients can see the physician’s visit notes?

e-Patient Dave | June 12, 2010

The opening anecdote of the e-patient white paper tells of a patient who impersonated a doctor in 1994, to get his hands on an article about an operation he was about to have. He got busted. Two years later episode 139 of Seinfeld had something similar – Kramer impersonates a doctor to try to get Elaine’s medical record: (Click to watch it on YouTube; they won’t allow embedding on other sites.)

It aired October 17, 1996. It was a turning point in American healthcare: eight weeks earlier the Health Insurance Portability and Accountability Act (HIPAA) had been signed into law, but the full regulations had not yet been written, so when this aired Elaine did not have a legal right to look at her record.

Today she does, though as we’ve written here (sample post from January, & comments), it’s often difficult. Plus, HIPAA regulations allow 30-60 days for providers to deliver, and states can set whatever price they want for the copies. (Regina Holliday was famously told her husband’s records would cost 73 cents a page.) But at least there’s a legal right.

Now, the Robert Wood Johnson Foundation (RWJF) is funding a study called OpenNotes to explore taking it a big step further: what happens if patients can see, online, every last bit of what their doctors are writing?
Patients were enthusiastic

Patients used the notes

Of those with notes available, 84% of Beth Israel Deaconess Medical Center patients and 92% of Geisinger Health System patients opened at least one note. At Harborview Medical Center, where patients were using the portal for the first time, 47% opened at least one note. And 20-42% (depending on the site) shared their notes with someone else, usually family members or relatives.

They reported important benefits

77-85% reported better understanding of their health and medical conditions. 77-87% felt more in control of their care. 70-72% said they took better care of themselves. 60-78% reported doing better with taking their medications.

They did not feel overwhelmed

Very few patients (1-8%) reported being confused, worried, or offended by what they read in their doctors’ notes.
Before we began, doctors were nervous about whether OpenNotes would interrupt their workflow or interfere with their relationships with patients.

Few doctors reported significant impacts on workflow

0-5% reported longer visits. 0-8% took more time addressing patients’ questions outside of visits. 0-21% reported taking more time writing notes. And an analysis of e-mail traffic before and during the trial showed that doctors overall did not receive more messages from patients.

A substantial minority of doctors reported changing their documentation

While the study did not examine individual notes, 3-36% of participating doctors reported changing the way they wrote about mental health, substance abuse, cancer, and obesity.

Many doctors described strengthened relationships with their patients

They cited enhanced trust, transparency, communication, and shared decision making.
At the End of the Study, Patients and Doctors Wanted to Continue

• 99% of patients wanted to continue

• 17-26% of docs preferred not to…
  – But when given the chance to stop, none did

• 85-89% of patients said availability of open notes would influence their choice of providers and health plans
Obstacle to adoption: “Patients don’t understand this stuff”
If the data’s unclear let’s MAKE it clear

Like other industries do.
<table>
<thead>
<tr>
<th>Test Name</th>
<th>Unit</th>
<th>Low</th>
<th>High</th>
<th>Reference Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>WBC</td>
<td></td>
<td></td>
<td></td>
<td>5.0-10.0 Thousand/cu. mm</td>
</tr>
<tr>
<td>RBC</td>
<td></td>
<td></td>
<td></td>
<td>4.3-5.8 Nl/cu. mm</td>
</tr>
<tr>
<td>Hgb</td>
<td>g/dL</td>
<td>12.0</td>
<td>18.0</td>
<td>12.0-18.0 g/dL</td>
</tr>
<tr>
<td>Hct</td>
<td>%</td>
<td>35.0</td>
<td>50.0</td>
<td>35.0-50.0 %</td>
</tr>
<tr>
<td>MCH</td>
<td>pg</td>
<td>25.0</td>
<td>32.0</td>
<td>25.0-32.0 pg</td>
</tr>
<tr>
<td>MCHC</td>
<td>g/dL</td>
<td>29.0</td>
<td>32.0</td>
<td>29.0-32.0 g/dL</td>
</tr>
<tr>
<td>RDW</td>
<td></td>
<td></td>
<td></td>
<td>12.0-15.0 %</td>
</tr>
<tr>
<td>Platelets</td>
<td>10^9/L</td>
<td>150.0</td>
<td>450.0</td>
<td>150.0-450.0 10^9/L</td>
</tr>
<tr>
<td>Lymphocytes</td>
<td></td>
<td></td>
<td></td>
<td>0.3-1.0 Nl/cu. mm</td>
</tr>
<tr>
<td>Monocytes</td>
<td>10^9/L</td>
<td>0.0</td>
<td>0.5</td>
<td>0.0-0.5 10^9/L</td>
</tr>
<tr>
<td>Neutrophils</td>
<td></td>
<td></td>
<td></td>
<td>50-70 %</td>
</tr>
<tr>
<td>Eosinophils</td>
<td></td>
<td></td>
<td></td>
<td>0.5-5.0 %</td>
</tr>
<tr>
<td>Basophils</td>
<td></td>
<td></td>
<td></td>
<td>0.0-1.0 %</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>80-100 %</td>
</tr>
</tbody>
</table>

Source: [Wired](https://www.wired.com)
Your Test Results

**Patient:** Cora Peterson

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>DOB</th>
<th>Ordered By</th>
<th>Collected</th>
<th>Received</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>41</td>
<td>August 12, 1969</td>
<td>Dr. Pico Duval</td>
<td>November 13, 2010, 8:40 a.m.</td>
<td>November 13, 2010, 8:12 p.m.</td>
</tr>
</tbody>
</table>

**Results:**

### Comprehensive Metabolic Panel

- **Glucose (fasting):** 125 mg/dL

<table>
<thead>
<tr>
<th>Normal</th>
<th>Prediabetes</th>
<th>May Indicate Diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 100</td>
<td>100 to 125</td>
<td>&gt; 125</td>
</tr>
</tbody>
</table>

**YOU:** 125

### Lipid Profile

- **Total cholesterol:** 211 mg/dL

<table>
<thead>
<tr>
<th>Desirable</th>
<th>Borderline</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 200</td>
<td>200 to 240</td>
<td>&gt; 240</td>
</tr>
</tbody>
</table>

**YOU:** 211

- **HDL ("good" cholesterol):** 46 mg/dL

<table>
<thead>
<tr>
<th>Low</th>
<th>Normal</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 50</td>
<td>&gt; 50</td>
<td></td>
</tr>
</tbody>
</table>

**YOU:** 46

- **LDL ("bad" cholesterol):** 165 mg/dL

<table>
<thead>
<tr>
<th>Optimal</th>
<th>Near-Optimal</th>
<th>Borderline</th>
<th>High</th>
<th>Very High</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 100</td>
<td>100 to 129</td>
<td>130 to 159</td>
<td>160 to 190</td>
<td>&gt; 190</td>
</tr>
</tbody>
</table>

**YOU:** 165

### Vitamin D

- **Total vitamin D:** 22 ng/mL

<table>
<thead>
<tr>
<th>Deficiency</th>
<th>Insufficiency</th>
<th>Sufficiency</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 20</td>
<td>20 to 30</td>
<td>31 to 100</td>
</tr>
</tbody>
</table>

**YOU:** 22

### Complete Blood Cell Count (CBC)

Normal for all 20 values, including white blood cell count (a high count can indicate infection).

### Urinalysis

Normal for all 20 values, including color, appearance, and protein.

### Questions?

Contact the physician who ordered this test for further interpretation of the results:

DR. PICO DUVAL
(212) 555-5253
Same data – better software.
Information: clearer.
Consumer: informed, enabled.
Clarity is power.
Psoas muscle
(My kidney tumor was encroaching on it)
Why not “Google Earth for my body”?
Objection:

“‘My patients aren’t like that.’”

“‘They aren’t asking for this.’”
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.

National Association OPPOSED to Woman Suffrage

Headquarters
268 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?
At last, 2012: recognition from the establishment
**TABLE S-3. Characteristics of a Continuously Learning Health Care System**

<table>
<thead>
<tr>
<th>Science and Informatics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Real-time access to knowledge</strong>—A learning health care system continuously captures, curates, and delivers the best available evidence to guide, support clinical decision making and improve care safety and quality.</td>
</tr>
<tr>
<td><strong>Digital capture of the care experience</strong>—A learning health care system captures and shares the experience on digital platforms for real-time generation and application to improvement.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Patient-Clinician Partnerships</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Engaged, empowered patients</strong>—A learning health care system is anchored in patient perspectives and promotes the inclusion of patients, families, and other members of the continuously learning care team.</td>
</tr>
</tbody>
</table>
Yes, the IOM itself says e-patients are an essential part of tomorrow’s healthcare.

**Patient-Clinician Partnerships**

*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.
e-Patients Can Help Improve Healthcare

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Skype: ePatientDave