The Rise of e-Patients
How three tech revolutions have changed medicine

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The story of e-patients (and netweavers)
Trudy and Peter Johnson-Lenz
New social operating system: Networked Individualism

• Social networks are more important
• Social networks are differently composed
• Social networks perform different functions
• Social networks are more vivid and tied to creation of information/media
Implications of networking individualism for health care

• Social networks (and the internet) provide “second opinions” – and can be sources of misinformation
• Providers are necessarily “nodes” in people’s social networks
• Social networks are allies and complements for care delivery
• Those in acute care use their networks differently from those with chronic conditions
• Providers are assessed and judged in more public ways
Digital Revolution 1: Broadband Internet (85%) and Broadband at home (66%)

Broadband and dial-up adoption, 2000-2012

% of American adults who access the internet at home via dial-up or broadband, over time. As of April 2012, 66% of American adults age 18+ have a high-speed broadband connection at home.
Networked creators among internet users

- 69% are social networking site users
- 59% share photos and videos
- 37% contribute rankings and ratings
- 33% create content tags
- 30% share personal creations
- 26% post comments on sites and blogs
- 15% have personal website
- 15% are content remixers
- 16% use Twitter
- 14% are bloggers
- ... of smartphone owners, 18% share their locations; 74% get location info and do location sharing
55% of adults own **laptops** – up from 30% in 2006

50% of adults own **DVRs** – up from 3% in 2002

45% of adults own **MP3 players** – up from 11% in 2005

42% of adults own **game consoles**

25% of adults own **tablet computer** – iPad, Kindle Fire

21% of adults own **e-book readers** - Kindle
Impact on health

- Empowered and engaged – 61% of all adults get health info online (80% of internet users)
- Participatory e-patients – 60% consume social media; 29% have contributed content
- Crowd-sourced via e-patients: 19% consult rankings/reviews of providers (5% post them); 18% consult reviews of hospitals (4% post them)
Anti-Hippocratic Age

I SWEAR ... I will impart a knowledge of the Art to my own sons, and those of my teachers, and to disciples bound by a stipulation and oath according to the law of medicine,

but to none others.
AMA press release
December 20, 2001

6. Remember that the Internet cannot replace a physician’s expertise and training .... If you have questions, trust your physician, not a chat room
### Demographic factors correlated w/ broadband adoption

<table>
<thead>
<tr>
<th>Positive correlation (in order of importance)</th>
<th>Negative correlation (in order of importance)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household income of $75,000 or more per year</td>
<td>Having high school degree or less</td>
</tr>
<tr>
<td>College degree</td>
<td>Senior citizen (age 65+)</td>
</tr>
<tr>
<td><strong>Parent with minor child at home</strong></td>
<td>Rural resident</td>
</tr>
<tr>
<td>Married or living with partner</td>
<td>Disabled</td>
</tr>
<tr>
<td>Employed full time</td>
<td>African-American</td>
</tr>
</tbody>
</table>

Source: Pew Internet Project, August, 2011 tracking survey
By the numbers: Who’s not online?

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>17%</td>
<td>...of American adults are not online</td>
</tr>
<tr>
<td>34%</td>
<td>of them have some past or current contact w/ internet</td>
</tr>
<tr>
<td>10%</td>
<td>of them want to use the internet in the future</td>
</tr>
<tr>
<td>61%</td>
<td>of them would need assistance getting online</td>
</tr>
</tbody>
</table>

Source: Pew Internet Project, May 2010 tracking survey
Relevance & digital literacy are primary factors for not going online

- Relevance: 48%
- Price: 21%
- Usability: 18%
- Availability: 6%
- Other: 7%

Source: Pew Internet Project, May 2010 tracking survey
Revolution 2: Mobile – 89% of adults

Mobile Subscriber Connections in America

Total U.S. population: 315.5 million

Source: CTIA
Changes in smartphone ownership

- May 2011: Smartphone ownership increased from 35% to 46%.
- February 2012: Smartphone ownership increased from 48% to 41%.
- No cell phone ownership decreased from 17% to 12%.
The rise of apps culture - 50% of adults

Download apps to their phone
- Sept 2009: 22%
- May 2010: 29*
- August 2011: 38*

Have preloaded apps on their phone
- Sept 2009: 38%
- May 2010: 43*
- August 2011: 43

Total who have apps on phone
- Sept 2009: -20%
- May 2010: 0%
- August 2011: 50*
Mobile health apps

- All (n=658): 29%
- Urban (n=203): 33%*
- Suburban (n=322): 29%*
- Rural (n=100): 20%
- 18-29 (n=224): 28%*
- 30-49 (n=276): 32%*
- 50+ (n=145): 20%
Impact on health

- Real-time – 35+% use mobile phone for health info; 29% have health apps on handhelds
- Place-less and time-less
- Over-represented among young, minorities, urban residents, upper SES
- **NO FEMALE/MALE DIFFERENCES**
Digital Revolution 3
Social networking – 52% of all adults

% of internet users

2005 2006 2007 2008 2009 2010 2011 2012

18-29 30-49 50-64 65+

Pew Internet
Pew Internet & American Life Project
Impact on health

- “Last search”: 48% for others; 36% for self; 11% for both
- Read others’ commentaries: 34%
- Find others who have same condition: 18%
- Get info from social networking site: 11% SNS users
- Get info from Twitter: 8% of Twitter users
How people make medical decisions

- Mindset – general approach to medicine
- Data/Numbers – and how they are presented
- Stories
How online searches affect decisions (1)

- 60% of e-patients say the information found online affected a decision about how to treat an illness or condition.
- 56% say it changed their overall approach to maintaining their health or the health of someone they help take care of.
- 53% say it lead them to ask a doctor new questions, or to get a second opinion from another doctor.
How online searches affect decisions (2)

- 49% say it changed the way they think about diet, exercise, or stress management.
- 38% say it affected a decision about whether to see a doctor.
- 38% say it changed the way they cope with a chronic condition or manage pain.
## The networked world of e-patients

<table>
<thead>
<tr>
<th>What providers are good for</th>
<th>What others are good for</th>
</tr>
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<tbody>
<tr>
<td>- Diagnosis / treatments</td>
<td>- Emotional support</td>
</tr>
<tr>
<td>- Prescriptions</td>
<td>- Practical advice for day-to-day coping</td>
</tr>
<tr>
<td>- Recommendation for specialist</td>
<td>- Recommendation for quick remedy for everyday issue</td>
</tr>
<tr>
<td>- Recommendation for hospital</td>
<td></td>
</tr>
<tr>
<td>- Info on alternative treatments</td>
<td></td>
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What’s a doctor to do about e-patients?

• Minimum engagement
  – “Tell me what you’re thinking” - Groopman
  – Ask about patients’ internet use, exposure on social networking, what they post and read

• Medium engagement
  – Ask if patients would be willing to be let you/staff be a node on social media

• Heavy engagement
  – Do it yourself
What social networks do for patients:
Why physicians can be “nodes”

- **Attention** – *act as sentries*
  - alerts, social media interventions, pathways through new influencers
- **Assessment** – *act as trusted, wise companion*
  - help assess the accuracy of info, timeliness of info, transparency and rigor of info
- **Action** – *act as helpful producers/enablers*
  - help give people outlets for expression, interpretation of their creations
Health outcomes payoff

• Monitoring
• Interventions and reinforcement
• Skills training – meds/devices
• Emotional and social support among peers
• “Information prescriptions”
• Amateur research contributions – online recruitment, communities and clinical trials
Be not afraid
Thank you!