

A Perspective on Transparency

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Portland, Oregon

Aligning Quality and Value in Hematopoietic Cell Transplantation
Minneapolis, Minnesota
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Disclosures

- General internist, MPH, decades of administrative work
- No financial relationships, volunteer for OpenNotes
- Accept “markets” as a reality but market settings are often not a “level playing field.”
- Advertising and promotion are an effective means of providing biased information to consumers leading to frequent overuse or misuse.
- Consumers need independent, scientific information to make optimal selections.
- 2 personal experiences

HEALTH CARE ADVERTISING

NOW



SOMEDAY??



Viewpoint

(Delbanco, et al, *Health Expect*, 2001)

Healthcare in a land called PeoplePower: nothing about me without me

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Abstract

In a 5-day retreat at a Salzburg Seminar attended by 64 individuals from 29 countries, teams of health professionals, patient advocates, artists, reporters and social scientists adopted the guiding principle of 'nothing about me without me' and created the country of PeoplePower. Designed to shift health care from 'biomedicine' to 'infomedicine', patients and health workers throughout PeoplePower join in informed, shared decision-making and governance. Drawing, where possible, on computer-based guidance and communication technologies, patients and clinicians contribute actively to the patient record, transcripts of clinical encounters are shared, and patient education occurs primarily in the home, school

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THE DAY I STARTED LYING TO RUTH

PETER BACH MD
NEW YORK MAGAZINE
MAY 2014

“I don’t want my doctor knowing something about me that I don’t.”

Ruth Bach

Transparency


- Trust
 - Conflicts of interest—financial and academic
- Evidence based benefits and risks
- Performance measurement
- Patient experience
- Cost/Price transparency
- OpenNotes

Conflicts of Interest

- Large databases now make financial relationships with industry easy to identify
 - But fuzzy definitions of research versus marketing activity confuse
- NEJM/Pharmascolding
- Academic/intellectual conflicts though likely more powerful

Presentation on US Hospital Websites of Risks and Benefits of
Transcatheter Aortic Valve Replacement Procedures
JAMA Internal Medicine, January 12, 2015

- Review of websites of 317 hospitals participating in STS/ACC TAVR registry
- 262 had web pages with TAVR information
- 260 had benefit information
- 69 had risk information
- Benefits quantified on 97, risks on 12 ($P < .0001$)
- RCT shows TAVR has 2x risk of stroke of Open AVR



The art of surgery:

Minimally invasive procedures guided by the same surgeons who are teaching others their art.

At the University of Texas Medical Branch (UTMB Health), minimally invasive procedures are performed by the most talented and experienced surgeons using the most advanced laparoscopic and robotic technologies. These internationally recognized surgeons are the very people who you want taking care of you and your family. In fact, they are the doctors who are teaching others how to do what they do. The technology is breakthrough. The surgeons are the best. The benefits are numerous. Minimally invasive procedures are safe, and result in faster and easier recovery.

So if you are scheduling surgery for yourself or a loved one, be sure to ask if it can be done using a minimally invasive procedure at UTMB Health. The skills, the knowledge, the leadership and the confidence make the difference. It's all here in the Houston/Galveston Bay Area. This is what happens when the most talented surgeons use the most advanced surgical applications.

This is taking charge of your health.

utmb Health

Left: Guillermo Gomez, MD
Director of the Center for Obesity and Metabolic Surgery

Center Left: Joseph Sonstain, MD
Minimally Invasive Urologic Surgery

Center Right: Kimberly Brown, MD, FACS
Minimally Invasive Liver and Pancreatic Surgery

Right: Sami Gokhan Kiliç, MD, FACS, FACS
Chief of Minimally Invasive Gynecology & Research

The four surgeons featured here are representative of the more than thirty UTMB surgeons using state of the art minimally invasive surgical techniques across a wide variety of medical specialties.

Voluntary Disclosure

- Informing/encouraging/confirming
- Coordinating
 - Especially with marketing and communications
- Volunteers likely (but not always) better performers
- Unlikely selection explains the better performance of volunteers
- Describing the non participants
 - Never participants
 - Drop outs

Preparing for Public Disclosure

- NQRN
- Great data
- Reporting unit names, locations
- Consistency with other sources
- Presentation issues
 - Tiering
 - Symbols
 - Composites

Our Results

- 10 publications presenting physician performance
- High readership, high web traffic, increased news stand sales
 - All indication of demand
- NO data errors
- Name errors
- Major reader criticism—want results by individual physician

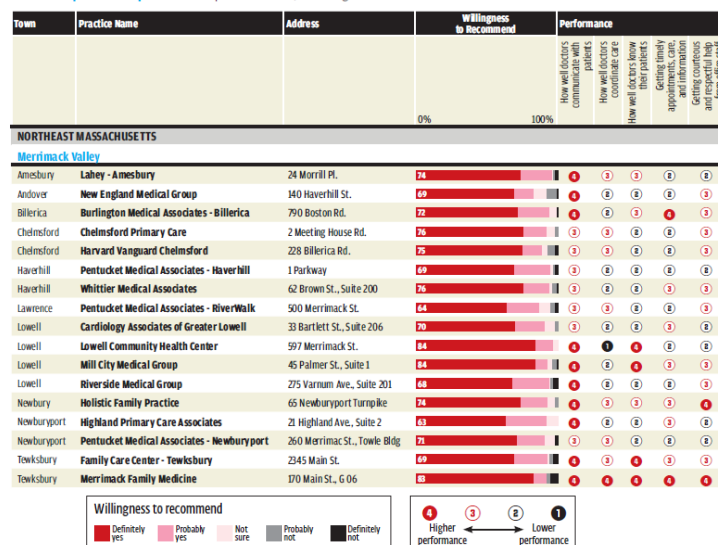
Patient Experience in Health

- Scientific approach or anecdotal (user reviews)
- Number of insurers, hospitals, doctors are a major challenge even with millions of respondents
- Hospital and health insurance CAHPS works well for us
- And so could doctors but a challenge
 - Directory a challenge
 - Collection costs substantial
 - Uniform approach that someone can afford??
 - Data at practice site and individual doctor level
 - User reviews tough competition

MASSACHUSETTS DOCTOR RATINGS

Ratings of practices for adults In collaboration with MHQP

Based on patient experience In alphabetical order, within regions and towns



© MHQP 2013

14

User Reviews at CR

- There is now a regular report that identifies products with significant disagreement between user reviews and CR ratings
- CR staff review those user reviews to determine if a reevaluation of performance measurement methods is needed, if the ratings should change, or other steps needed.
- CR acknowledges those differences on the ratings web page and reports it is trying to determine the reason for the discrepancy.

Conclusions

- Patient/consumer experience is a must for a complete sense of a product or service
- Robust physician experience surveys at an individual or even practice site level for the whole country are a huge challenge
- “Hello CR. Are you listening to our reviews.”
- We cannot ignore user reviews. They measure real consumer experience. They are affordable. They complement survey results.

Cost/Price Transparency

- Brill/Time Magazine
- Rosenthal/NY Times
- Obama transparency policies
- HealthcareBlueBook
 - 5x variation in same market
- FairHealth
- Castlight
- Guroo.com & HCCI
- State legislation
 - Population data versus individually actionable data

What is OpenNotes?

- Patients invited to review their providers' visit notes through secure patient portals
- Each patient notified automatically via e-mail message when a note has been signed...and reminded to review it before their next scheduled visit
- "OpenNotes" is an initiative to give patient's access to their EHR notes via the internet. Not a specific vendor product or software.
- Started with a research and demonstration project in 2010, involving more than 100 PCPs and 20,000 patients in Boston (BIDMC), rural Pennsylvania (Geisinger), and the Seattle inner city (Harborview)

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3 Overall Questions

- Does OpenNotes help patients become more engaged in their care?
 - YES
- Is OpenNotes the straw that breaks the doctor's back?
 - NO
- After living with this transparency, do patients and doctors want to continue?
 - YES, virtually 100%

Adapted from a presentation by Dr. David Blumenthal, MD, MPH, Harvard Medical School and Boston Children's Hospital, October 2014

19

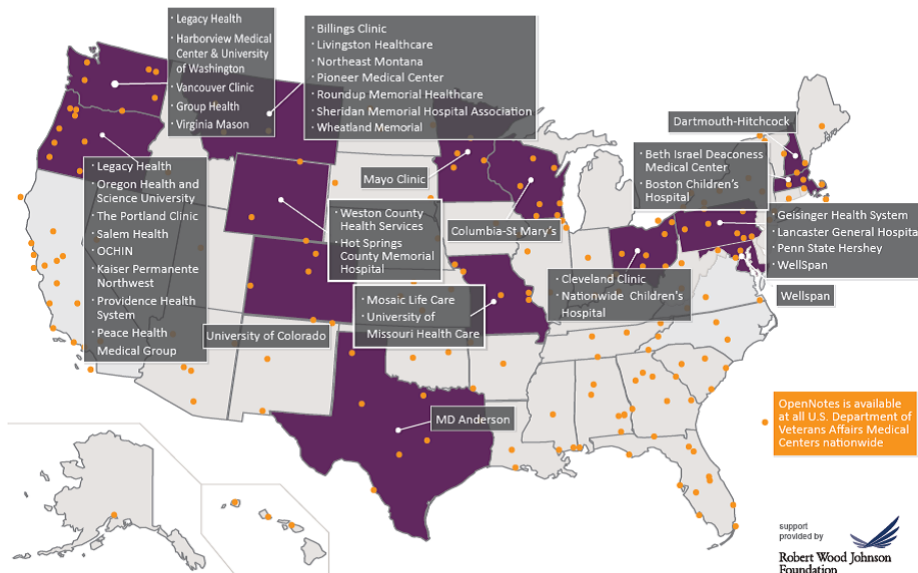
Kaiser Permanente Northwest: Early information on implementation

- Traffic to portal to review visit information up 400%
- MD email traffic flat
- Rare concerns from patients about care
- ¼ of 1% of notes are hidden by providers
- Mental health providers excluded
- Adolescents (13-18) excluded
- 7,000 notes per day now available to patients.

20



More than 5 million patients have easy access
to their clinicians' notes thanks to OpenNotes



THANK YOU

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