

## **Empowered, engaged, equipped and enabled: *Enabling the power of e-patients***

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**“e-Patient Dave” deBronkart**  
Patient Advocate and Activist



**MaryBeth Kurland, CAE**  
Chief Executive Officer  
Commission for Case Manager Certification

# Agenda

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- Welcome and Introductions
- Learning Objectives
- Presentation:
  - MaryBeth Kurland, CAE
  - e-Patient Dave deBronkart
- Question and Answer Session

# Audience Notes

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- There is no call-in number for today's event. Audio is by streaming only. Please use your computer speakers, or you may prefer to use headphones. There is a troubleshooting guide in the tab to the left of your screen. Please refresh your screen if slides don't appear to advance.
- Please use the "chat" feature below the slides to ask questions throughout the presentations. We will pose questions after the presentation and will address as many as time permits.
- A recording of today's session will be posted within one week to the Commission's website, [www.ccmcertification.org](http://www.ccmcertification.org)
- One continuing education credit is available for today's webinar only to those who registered in advance and are participating today.

# Learning Objectives Overview

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*After the webinar, participants will be able to:*

1. Communicate the World Bank's definition of empowerment and five levels of Arnsteins' Ladder of Citizen Participation;
2. Discuss the benefits for patients (and their caregivers) when they gain access to their own records and become engaged in their ongoing care; and
3. Describe three ways case managers can "let patients help."

## **Empowered, engaged, equipped and enabled: *Enabling the power of e-patients***

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**MaryBeth Kurland, CAE**  
**Chief Executive Officer**  
**Commission for Case Manager Certification**

- Webinars
- Certification Workshops
- Issue Briefs
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**CCM<sup>®</sup> CERTIFICATION** workshops



REPORT

DECEMBER 19, 2016



## Online Shopping and E-Commerce

*New technologies are impacting a wide range of Americans' commercial behaviors, from the way they evaluate products and services to the way they pay for the things they buy*

BY AARON SMITH AND MONICA ANDERSON



(Photo by Erik Isakson)

Americans are incorporating a wide range of digital tools and platforms into their purchasing decisions and buying habits,

**Roughly eight-in-ten Americans are online shoppers; 15% buy online on a weekly basis**

### REPORT MATERIALS



Complete Report PDF



Topline

### TABLE OF CONTENTS

#### Overview

1. Online shopping and purchasing preferences
2. Online reviews
3. New modes of payment and the 'cashless economy'

Acknowledgments

Methodology

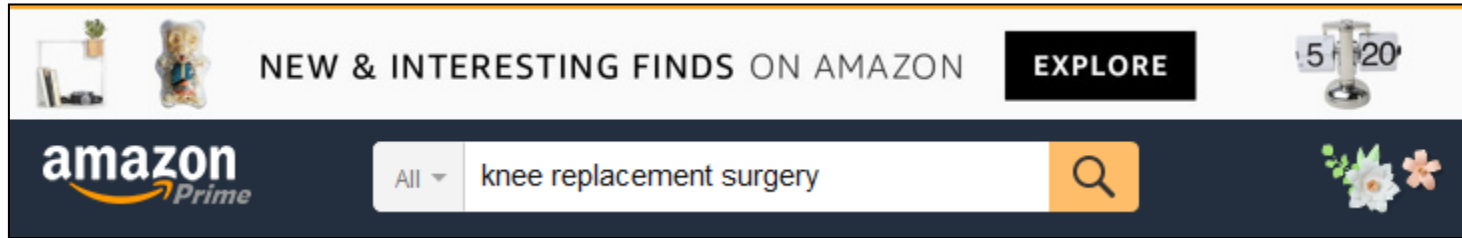
### RELATED

MULTI-SECTION REPORTS | NOV. 17, 2016

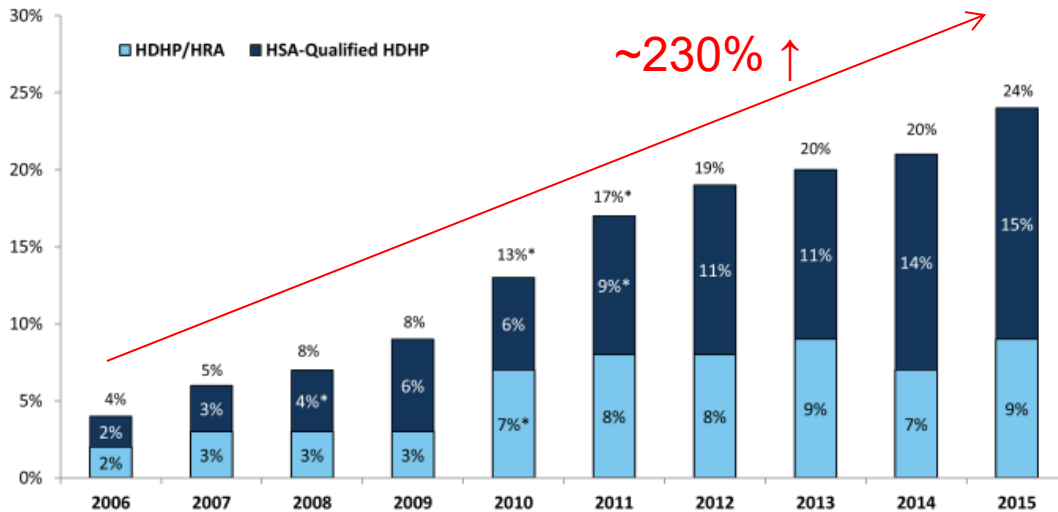
Consumers say it's important to be able to:

- 86%: Compare prices from different sellers
- 84%: Ask questions about what they are buying
- 84%: Buy from sellers they are familiar with
- 77%: Get advice from people they know
- 74%: Read reviews posted online

<http://www.pewinternet.org/2016/12/19/online-shopping-and-e-commerce/>



Percentage of Covered Workers Enrolled in an HDHP/HRA or HSA-Qualified HDHP, 2006-2015



- Average Silver plan deductible (ACA marketplace):
  - **\$3,572 individuals**
  - **\$7,474 for families**
- 20 million+ commercially insured Americans now in high-deductible plans
  - 13% in plans with annual out-of-pocket max of **\$6,000+**



**Patients say they want to be engaged in their health, too.**



Harvard Business Review

OPERATIONS

## Giving Patients an Active Role in Their Health Care

by Len Schlesinger and John Fox

NOVEMBER 21, 2016

SAVE SHARE **HH** TEXT SIZE PRINT **\$8.95** BUY COPIES

**FEATURE**

### HIMSS17: Patient engagement is all the rage, surveys find

## Introduction

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### **“e-Patient Dave” deBronkart**

Twitter: @ePatientDave

facebook.com/ePatientDave

LinkedIn.com/in/ePatientDave

dave@epatientdave.com

# Empowered, engaged, equipped, enabled: Enabling the power of e-patients

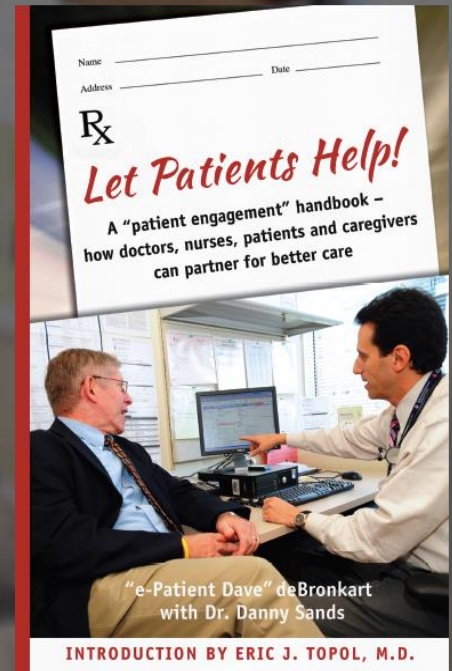
“e-Patient Dave” deBronkart

Twitter: @ePatientDave

facebook.com/ePatientDave

LinkedIn.com/in/ePatientDave

dave@epatientdave.com



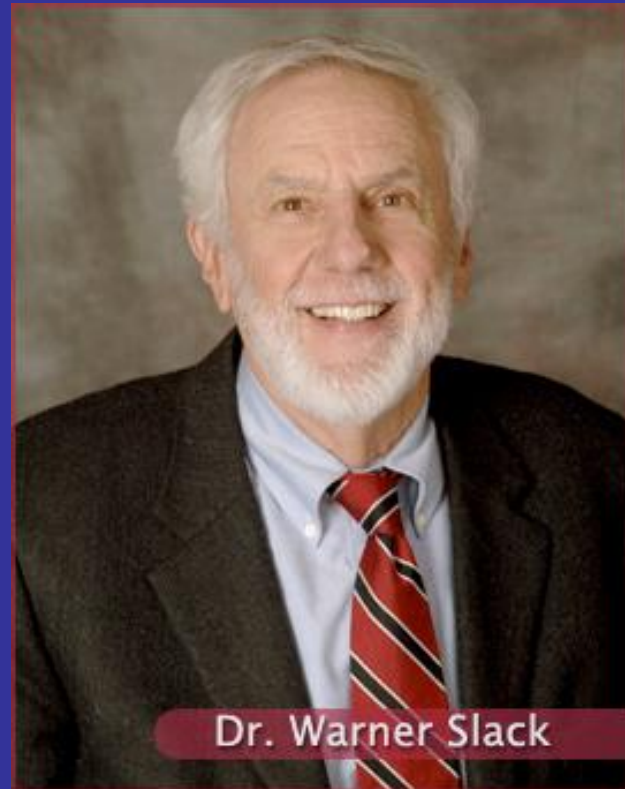
Bringing together e-patients and health care professionals.

# Objectives

- Communicate the World Bank's definition of empowerment and five levels of Arnstein's Ladder of Citizen Participation;
- Discuss the benefits for patients (and their caregivers) when they gain access to their own records and become engaged in their ongoing care;
- Describe 3 ways case managers can “let patients help.”

**“Patients are the most under-used resource in healthcare”**

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





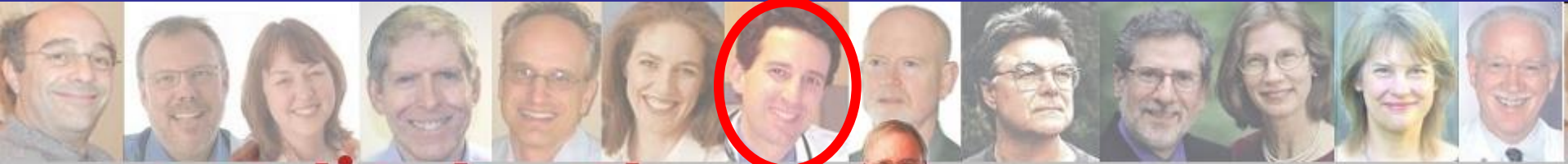
**e-patients.net**

because health professionals can't do it alone



e-Patients.net founder  
Tom Ferguson MD

1944-2006



**e-patients.net**

because health professionals can't do it alone



Doc Tom said,

“e-Patients are

**E**quipped

**E**ngaged

**E**mpowered

**E**nabled”





participatorymedicine.org

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*Participatory Medicine is a cooperative model of health care that encourages and expects active involvement by all connected parties (patients, caregivers, healthcare professionals, etc.) as integral to the full continuum of care.*

to promote clinical transparency among patients and their physicians through the exchange of information, via conferences, as well through the distribution of correspondence and other written materials.



The Society aims to advance the understanding of physicians and other professionals in the

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white paper

e-Patients:  
How They Can Help Us  
Heal Healthcare (PDF)

English (977 kb)

Español (962 kb)







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*Participatory Medicine is a cooperative model of health care that encourages and expects active involvement by all connected parties (patients, caregivers, healthcare professionals, etc.) as integral to the full continuum of care.*

## Society for Participatory Medicine

Community

Advocacy

Research

Education

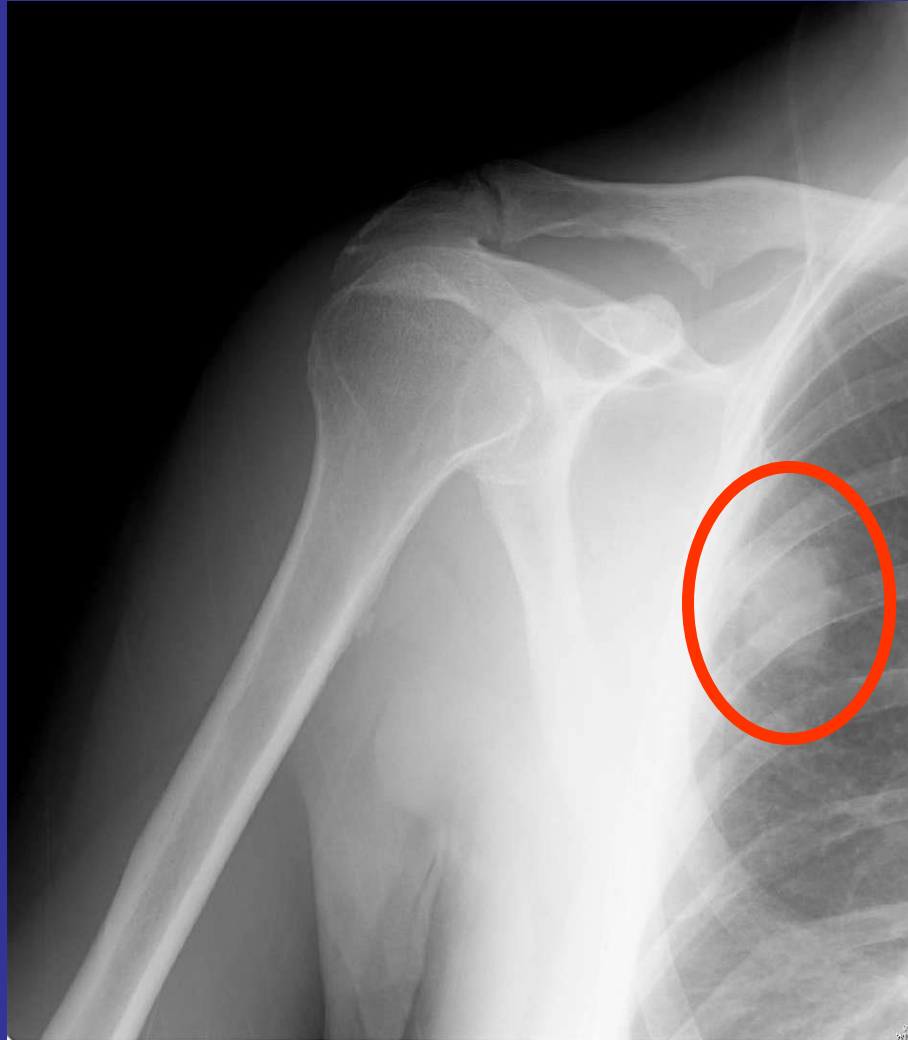
# The Incidental Finding

*Routine shoulder x-ray, Jan. 2, 2007*



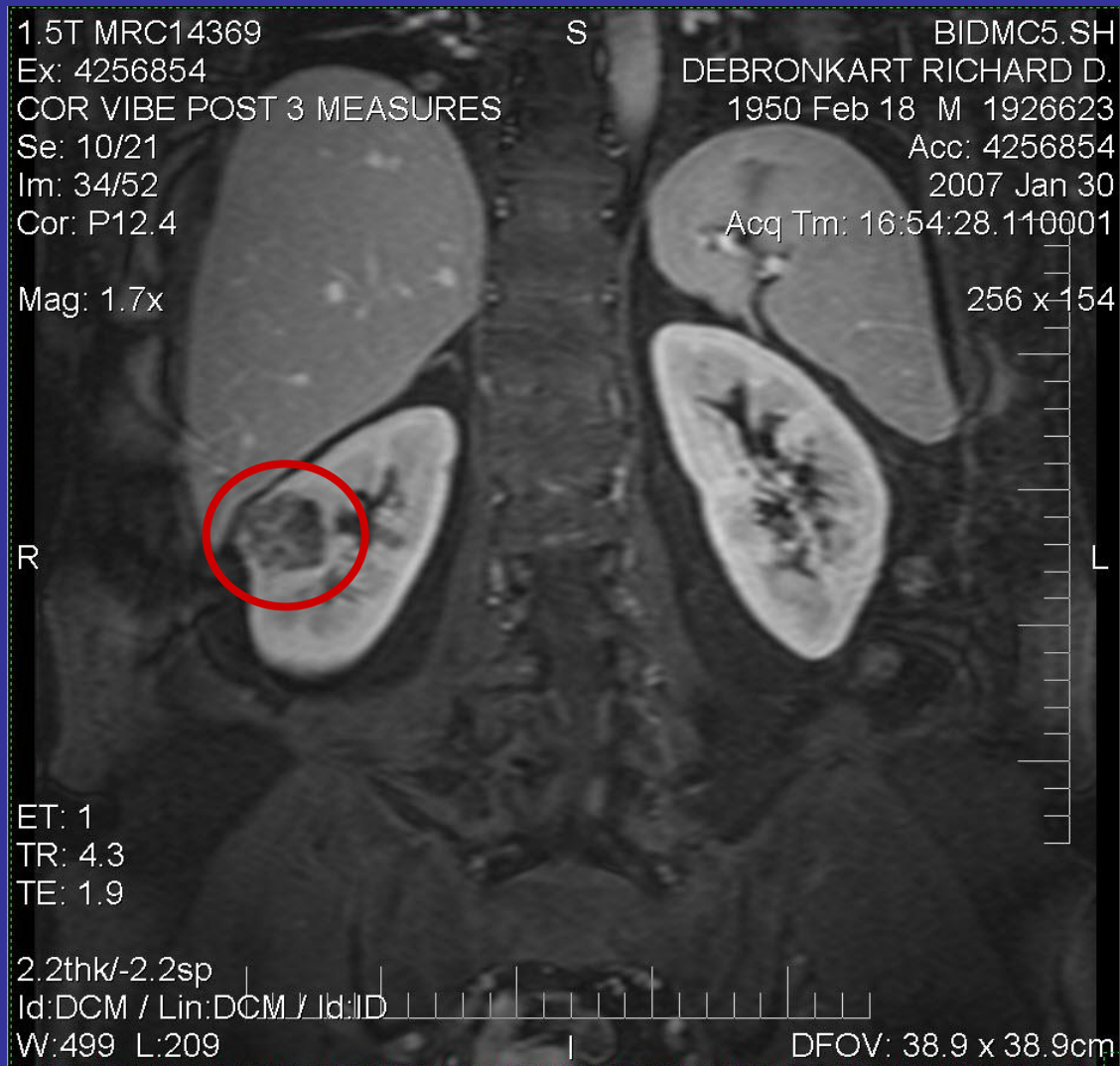
# The Incidental Finding

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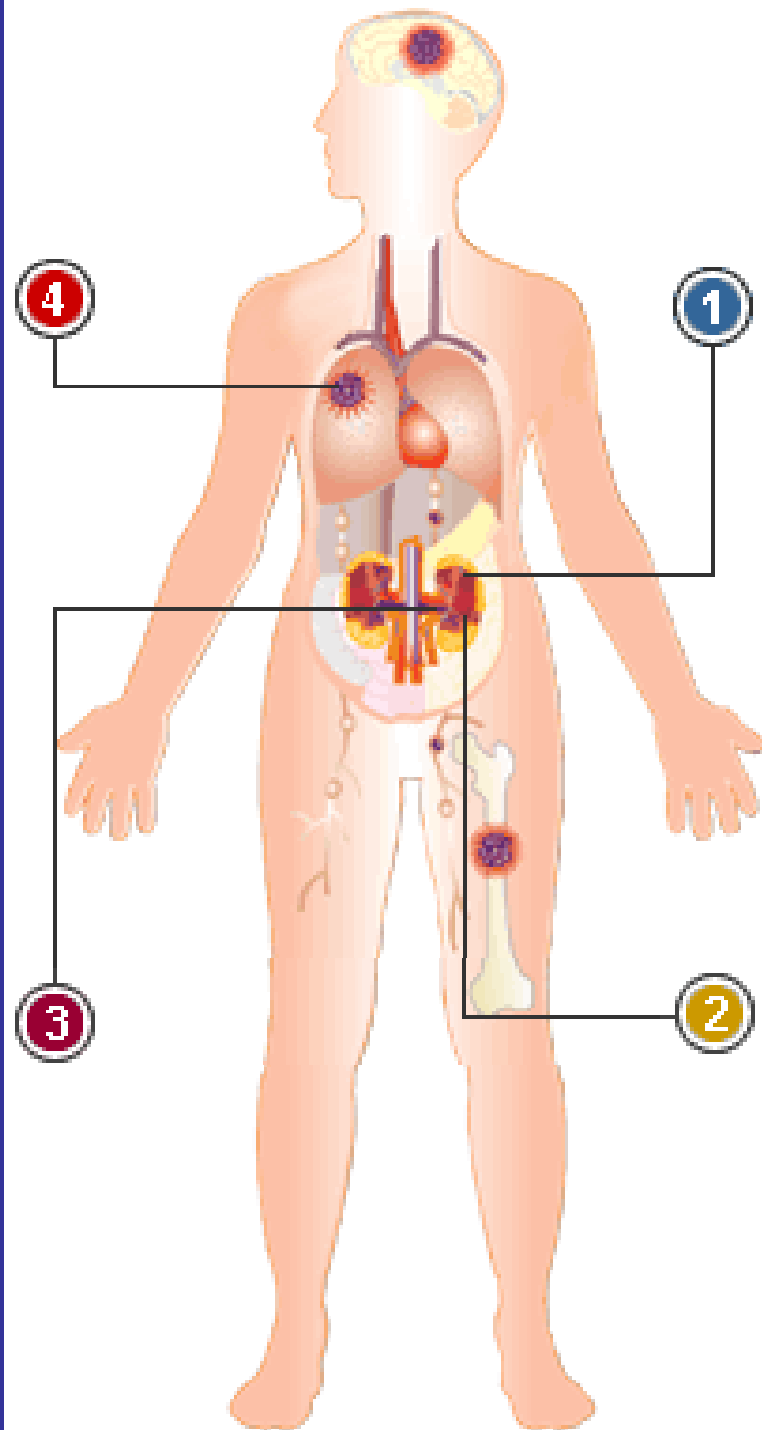
*“Your shoulder  
will be fine ...  
but there’s  
something  
in your lung”*

# Primary Tumor: Kidney



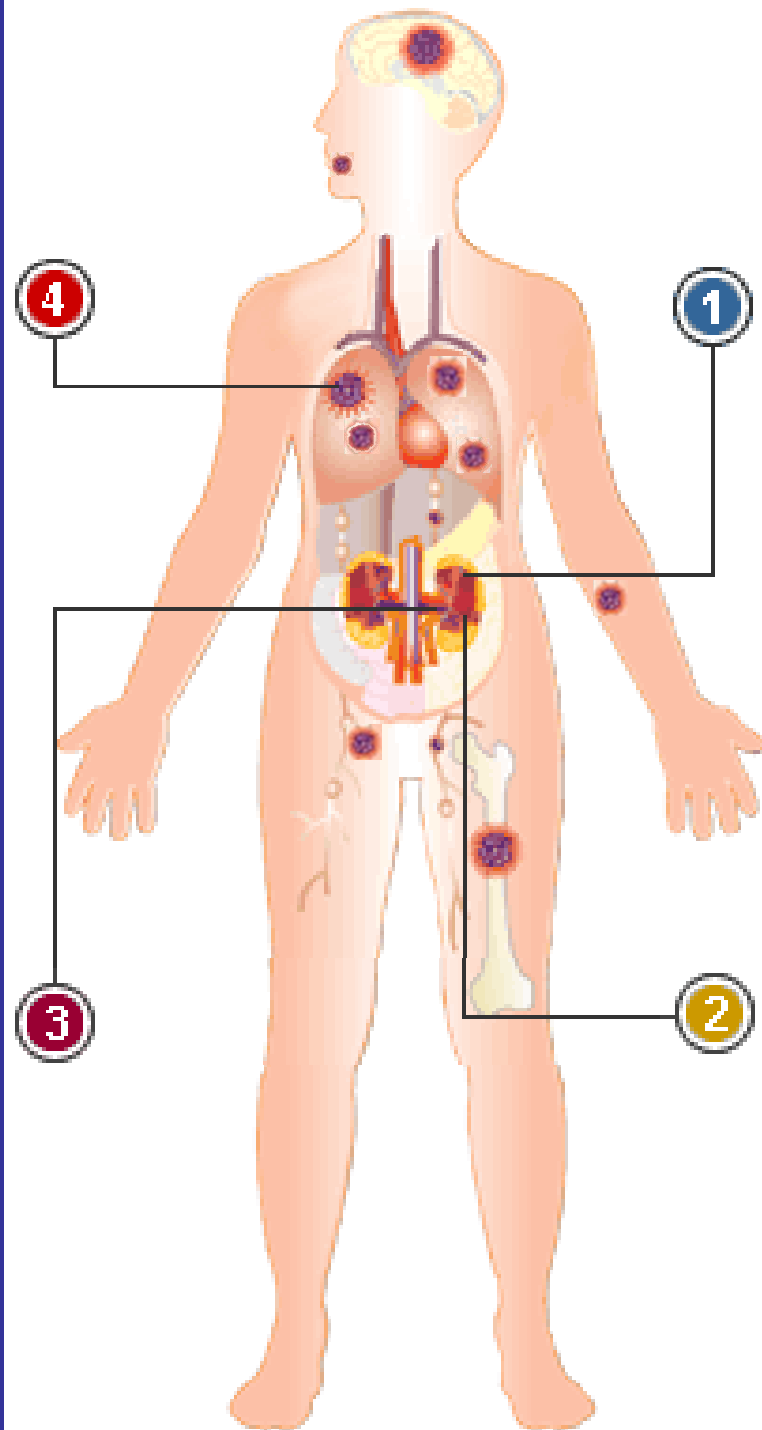
# Classic Stage IV, Grade 4 Renal Cell Carcinoma

*Illustration on  
the drug company's  
web site*



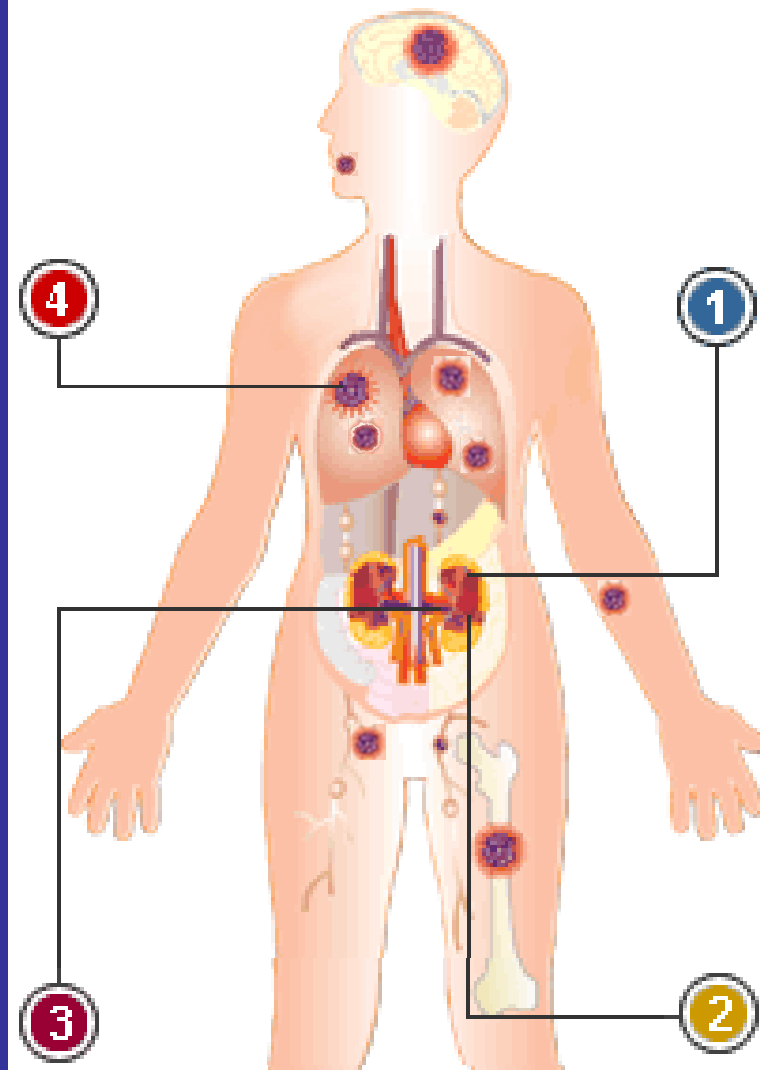
# Classic Stage IV, Grade 4 Renal Cell Carcinoma

*Illustration on  
the drug company's  
web site*



# Classic Stage IV, Grade 4 Renal Cell Carcinoma

*Illustration on  
the drug company's  
web site*



**Median Survival:  
24 weeks**

# E-Patient Activity 2:

## “My doctor prescribed ACOR”

*(Community of my patient peers)*

**acor.org**  
Association of Cancer Online Resources

The free online lifeline for everyone affected by cancer & related disorders

Home Dictionary Help Site Map

Find a mailing list Search

### WELCOME

Association of Cancer Online Resources

ACOR is a unique collection of online communities designed to provide timely and accurate information in a supportive environment.

ACOR offers access to mailing lists that provide support, information, and community to everyone affected by cancer and related disorders.

- MAILING LISTS
- SUPPORT & RESOURCES**
- TYPES OF CANCER**
- TREATMENT OPTIONS
- CLINICAL TRIALS
- PUBLICATIONS
- PARTNERSHIPS
- HELP ACOR

### News

**Fat tissue-derived hormone leptin increases e-cadherin expression, obesity-breast cancer link noted**  
Being obese increases the risk of breast cancer in post-menopausal women, shortens the time between return of the disease and lowers overall ...  
Apr 29, 2007  
[\[Full Story\]](#)

### What's New

**Please Note: Mar 26, 2007 Update: We have started**



# My patient peers told me:

- This is an uncommon disease –  
get to a hospital that does a lot of cases
- There's no cure, but HDIL-2 sometimes works.
  - When it does, about half the time it's permanent
  - **The side effects are severe.**
- Don't let them give you anything else first
- Here are four doctors in your area who do it
  - *And one of them was at my hospital*

“If you don’t want to die of kidney cancer then ...”

The game is to stay alive long enough for...

The screenshot shows the ACOR.org website. The logo 'acor.org' is prominently displayed, with the tagline 'Association of Cancer Online Resources' and 'The free online lifeline for everyone affected by cancer & related disorders'. A search bar is visible with the text 'Find a maili...'. On the right side, there is a vertical menu of navigation links, each with a play button icon. The links are: MAILING LISTS, SUPPORT & RESOURCES, TYPES OF CANCER, TREATMENT OPTIONS, CLINICAL TRIALS, PUBLICATIONS, PARTNERSHIPS, and HELP ACOR. The links 'SUPPORT & RESOURCES' and 'TYPES OF CANCER' are circled in red. Below the navigation menu, there is a 'WELCOME' section with the text 'ACOR is a unique collection of online communities designed to provide timely and accurate information in a supportive environment.' and a paragraph about mailing lists.

# “If you don’t want to die of kidney cancer then ...”

The game is to stay alive long enough for...

- ...something else to kill you

The screenshot shows the ACOR.org website. The logo "acor.org" is prominently displayed, with the tagline "The free online lifeline for everyone affected by cancer & related disorders" below it. The full name "Association of Cancer Online Resources" is also visible. A search bar and a "Find a mailing list" button are present in the top right. On the left, a "WELCOME" section provides a brief description of ACOR. On the right, a vertical menu lists various resources, with "SUPPORT & RESOURCES" and "TYPES OF CANCER" circled in red. Other menu items include MAILING LISTS, ONLINE COMMUNITIES, CURRENT TREATMENTS, CLINICAL TRIALS, EXPERIMENTAL TREATMENTS, PUBLICATIONS, CANCER-RELATED BOOKS, PARTNERSHIPS, ALLIANCES & FRIENDS, and HELP ACOR.

**acor.org**  
The free online lifeline for everyone affected by cancer & related disorders  
Association of Cancer Online Resources

Home | Dis

Find a mailing list

**WELCOME**  
Association of Cancer Online Resources

ACOR is a unique collection of online communities designed to provide timely and accurate information in a supportive environment.

ACOR offers access to mailing lists that provide support, information, and community to everyone affected by

- ▶ MAILING LISTS
  - ▶ ONLINE COMMUNITIES
- ▶ **SUPPORT & RESOURCES**
  - ▶ ... WITH CANCER
- ▶ **TYPES OF CANCER**
  - ▶ AN A-TO-Z LIST
- ▶ TREATMENT OPTIONS
  - ▶ CURRENT TREATMENTS
- ▶ CLINICAL TRIALS
  - ▶ EXPERIMENTAL TREATMENTS
- ▶ PUBLICATIONS
  - ▶ CANCER-RELATED BOOKS
- ▶ PARTNERSHIPS
  - ▶ ALLIANCES & FRIENDS
- ▶ HELP ACOR

# “If you don’t want to die of kidney cancer then ...”

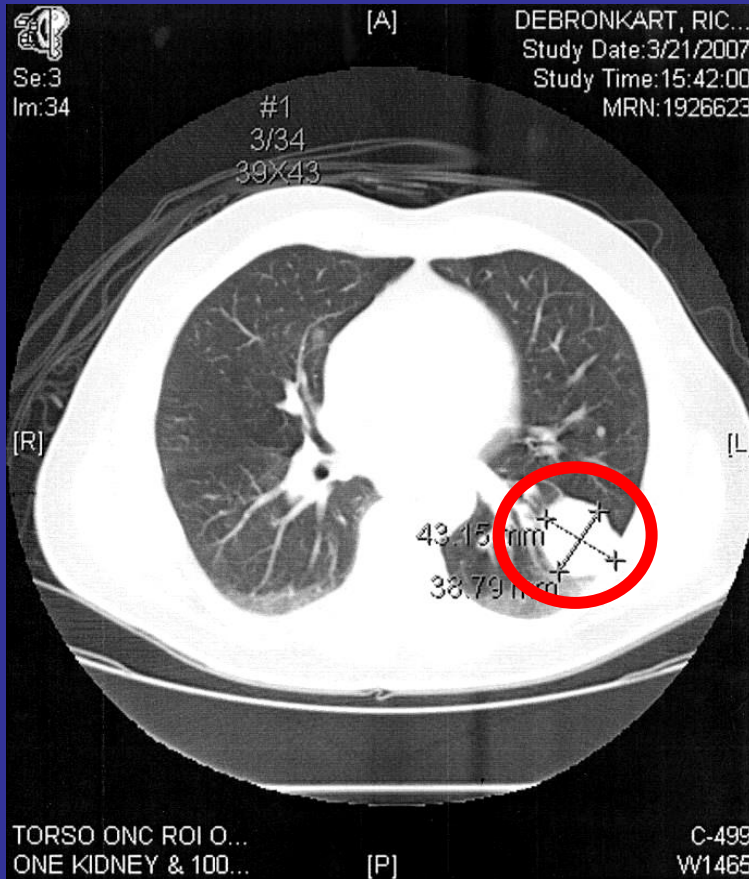
The game is to stay alive long enough for...

- ...something else to kill you
- ...the next treatment to come along

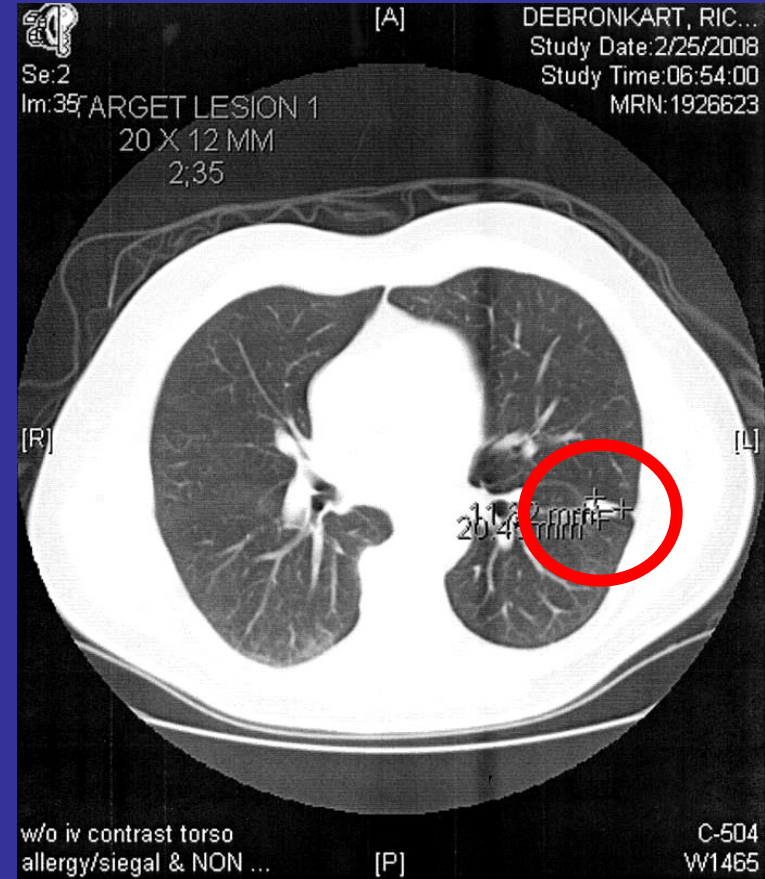
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# Surgery & Interleukin worked.

## Target Lesion 1 – Left Upper Lobe



Baseline: 39x43 mm



50 weeks: 20x12 mm

OPEN ACCESS: All **research articles** are freely available online, with no word limit. 
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## ANALYSIS

### Essay

# How the e-patient community helped save my life: an essay by Dave deBronkart

*BMJ* 2013; 346 doi: <http://dx.doi.org/10.1136/bmj.f1990> (Published 2 April 2013)  
 Cite this as: *BMJ* 2013;346:f1990

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Dave deBronkart, *policy adviser on patient engagement*

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### High HIV prevalence in Greece

Published 8 October 2013

### Gabapentin and pregabalin and their users

Published 8 October 2013

### Re: Military rather than civil answers for safer healthcare

Published 8 October 2013

### Re: Obese patients-doctors all, and cost of care may be obese

Published 8 October 2013

## 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 valuable—as in potentially lifesaving—information came from outside the establishment.

**How can it be  
that the most useful  
and relevant and  
up-to-the-minute information  
can exist outside of  
traditional channels?**



**Because of the Web, patients can connect to information and each other**



# Social Media: Information Capillaries



**Lesson:**  
**Environmental change**  
**can alter**  
**what's possible.**

**To miss this  
is to risk  
not noticing  
new options for action.**

**In addition to  
technological change,  
we're in an era of  
sociological change.**

# Empowerment

“Increasing the capacity  
of individuals or groups

# Empowerment

“Increasing the capacity  
of individuals or groups

to make choices [about what they want]

# Empowerment

“Increasing the capacity  
of individuals or groups  
to make choices [about what they want]  
and to transform those choices  
into desired actions & outcomes”



# 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*



OpenNotes

What happens  
when patients see  
their **providers'**  
actual notes??



isn't a product, it's a movement!

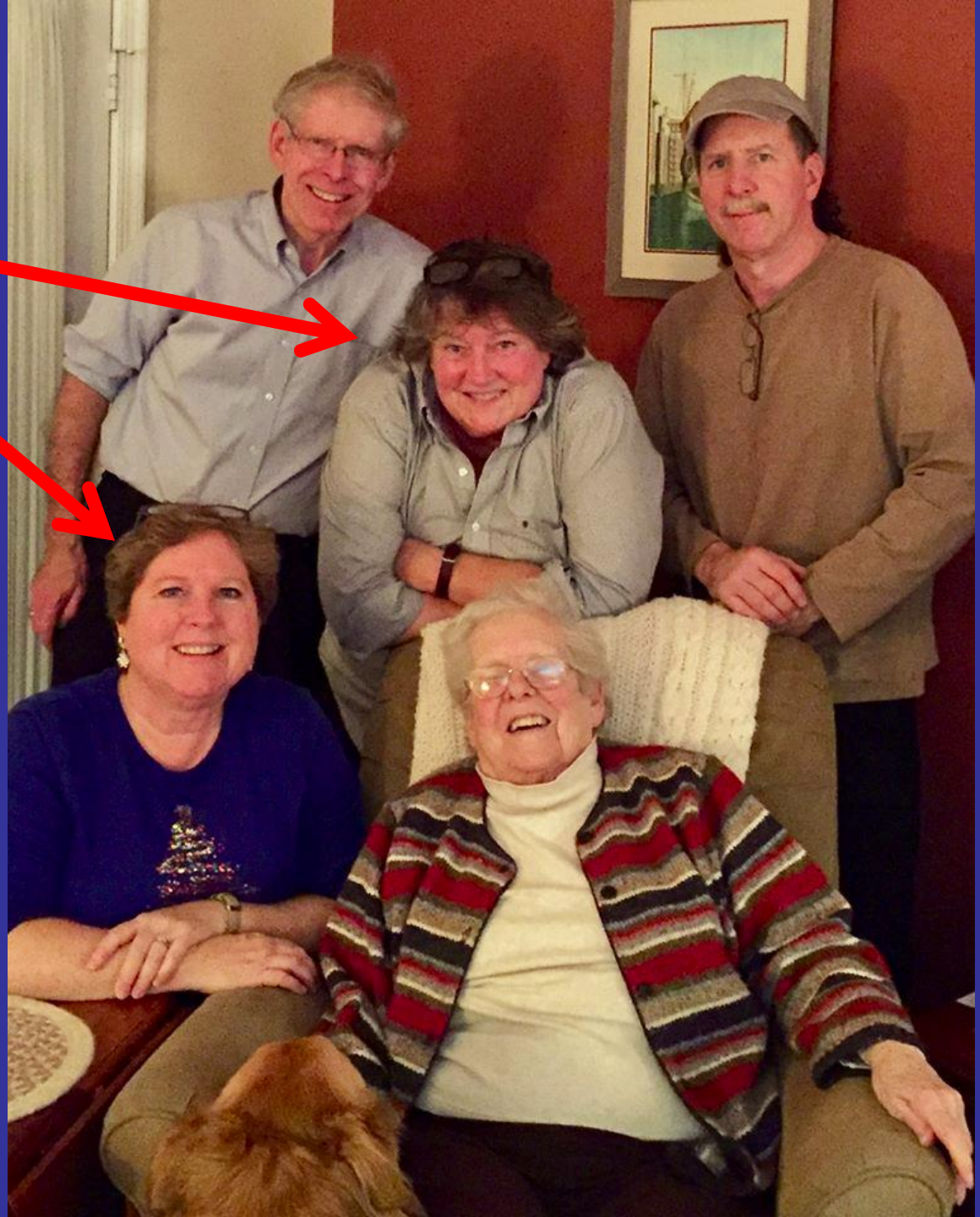
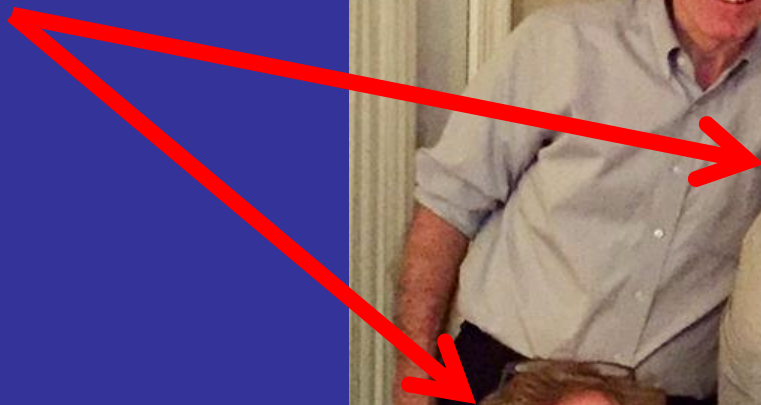
to allow patients to read  
their medical notes online,  
for free, whenever they want.

At the End of the Study, Patients and Doctors

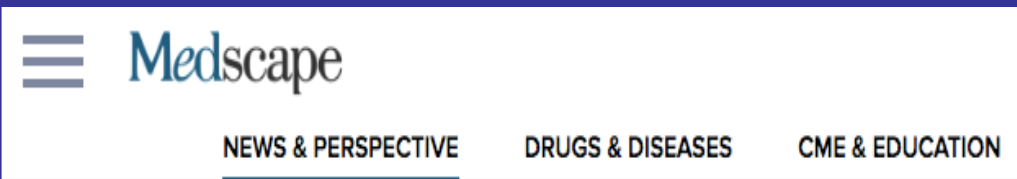
Wanted to Continue

- 99% of patients wanted to continue
- 17-26% of doctors 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 & health plans**

**My alpha sisters**



# Next advances: co-generation, agendas



News & Perspective

## OurNotes Project to Explore Patient-Generated EHR Data

Ken Terry

February 03, 2015

Beth Israel Deaconess Medical Center in Boston, Massachusetts, one of the pilot sites for the successful OpenNotes project, is [launching a study](#) called OurNotes to test the concept of having patients add to and update their own electronic medical records.

Using a \$450,000 grant from the Commonwealth Fund, the medical center will collaborate with its original OpenNotes study partners, the Geisinger Health System of Danville, Pennsylvania, and Harborview Medical Center in Seattle, Washington. Also included in the project are two other organizations that use OpenNotes: Seattle's Group Health Cooperative and Mosaic Life Care in St. Joseph, Missouri.

<http://www.medscape.com/viewarticle/839154>

doi: 10.1370/afm.2036Ann Fam  
Med March/April 2017vol. 15 no. 2 158-161

# Next advances: co-generation, agendas

News & Perspective

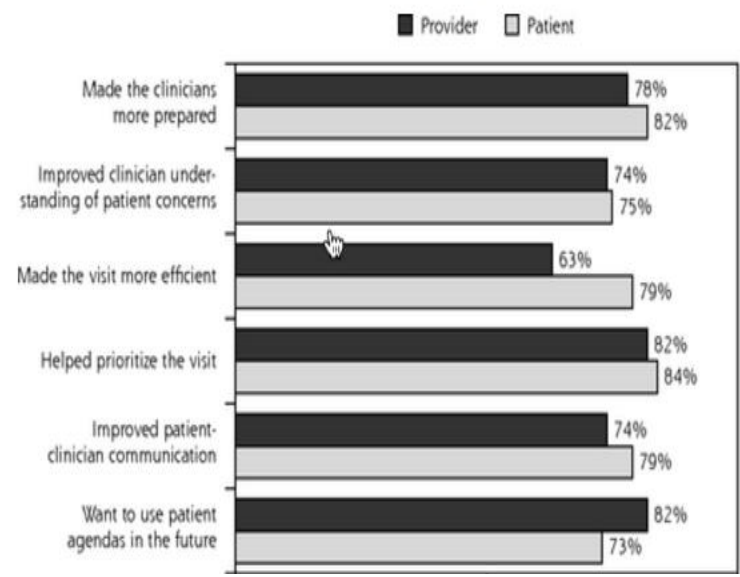
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## Patients Typing Their Own Visit Agendas Into an Electronic Medical Record: Pilot in a Safety-Net Clinic



*Beware a mental trap:*  
**“Patients wouldn’t  
understand this.”**



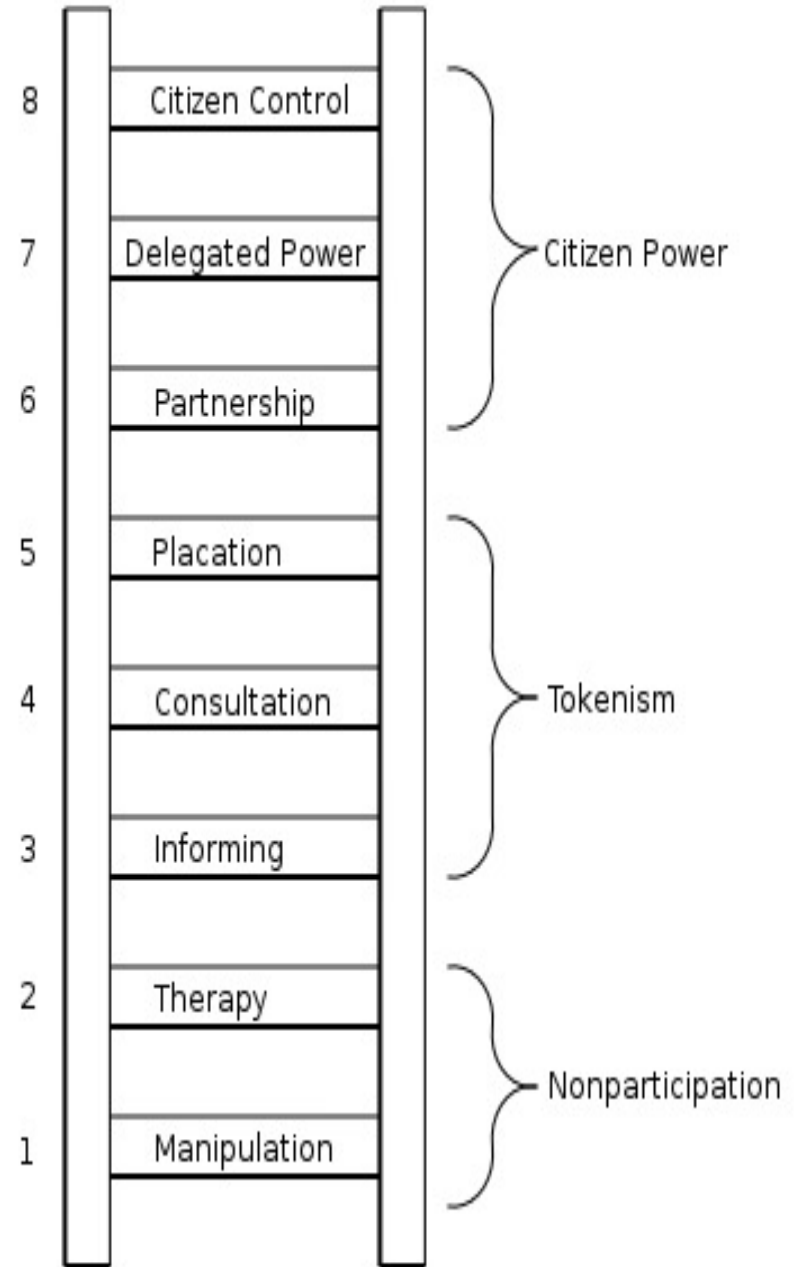
**It's perverse  
to keep someone in the dark  
then say they're ignorant.**

**A practical working model  
of levels of engagement  
(from citizen participation)**

# Arnstein's Ladder of Citizen Participation (1969)

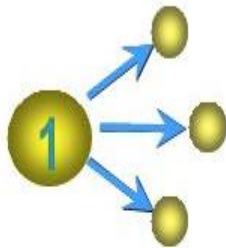
From the urban planning literature

By DuLithgow - As part of publishing an article online  
Previously published: <http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html>, CC BY 3.0,  
<https://commons.wikimedia.org/w/index.php?curid=47903791>



# Citizen Participation level I: “Here’s what we’re doing”

## Levels of Public Participation

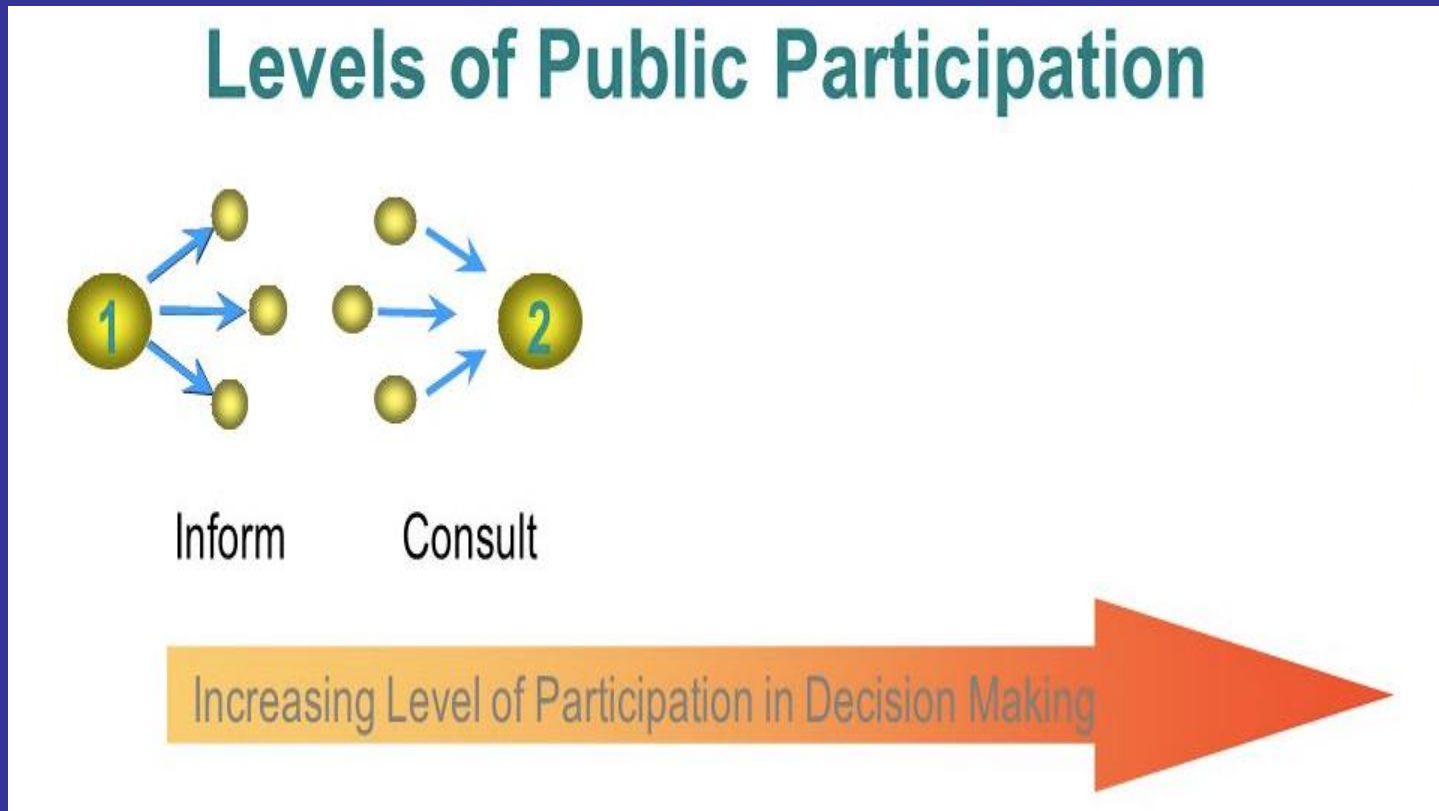


Inform

Increasing Level of Participation in Decision Making

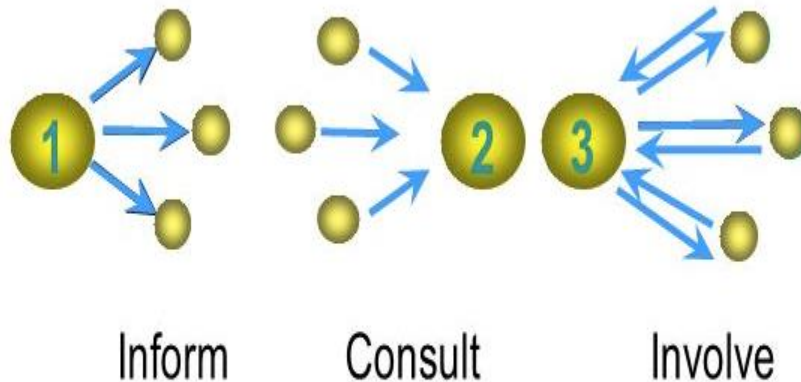
## Citizen Participation level 2:

“What do you *think* about what we’re doing?”



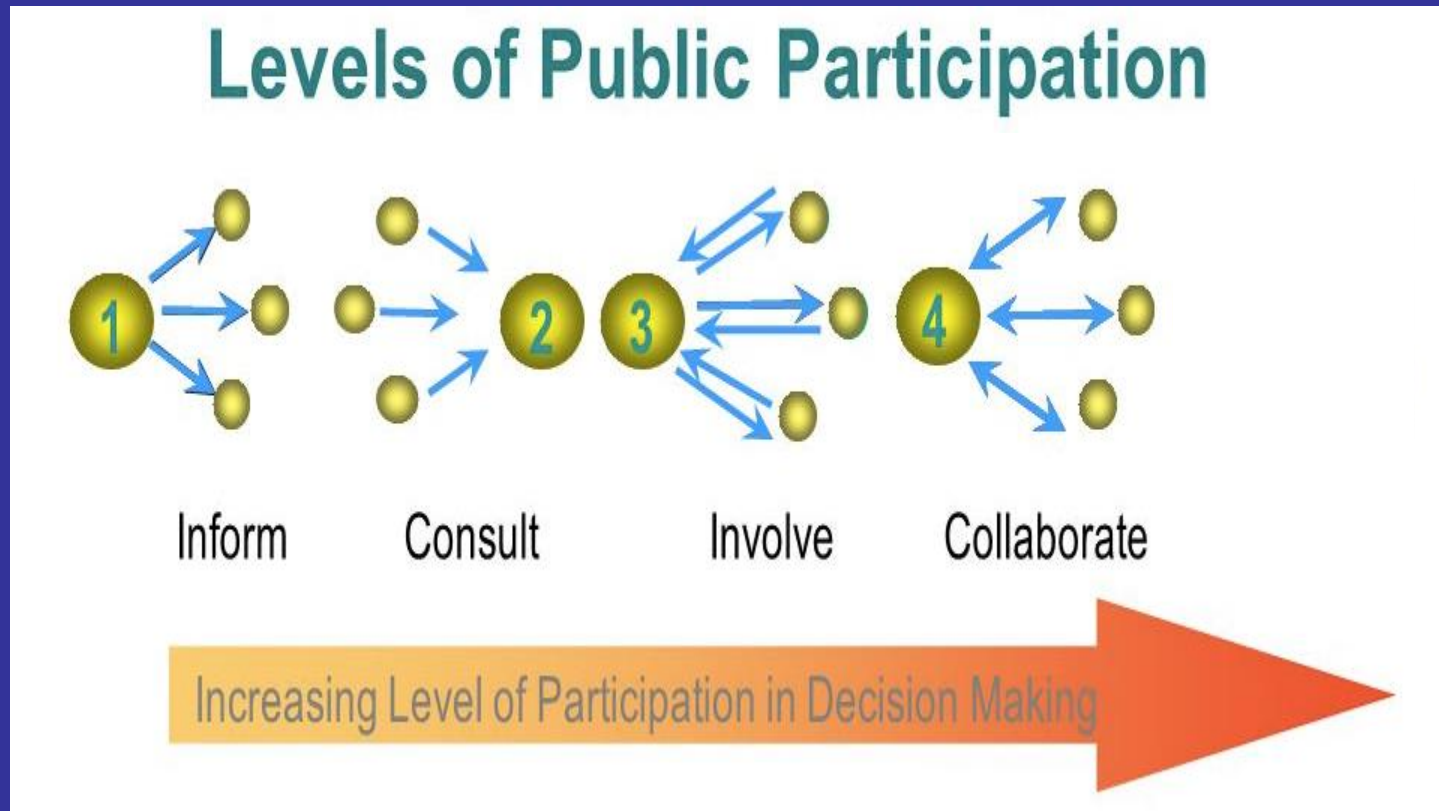
# Citizen Participation level 3: Involving the public in your work

## Levels of Public Participation

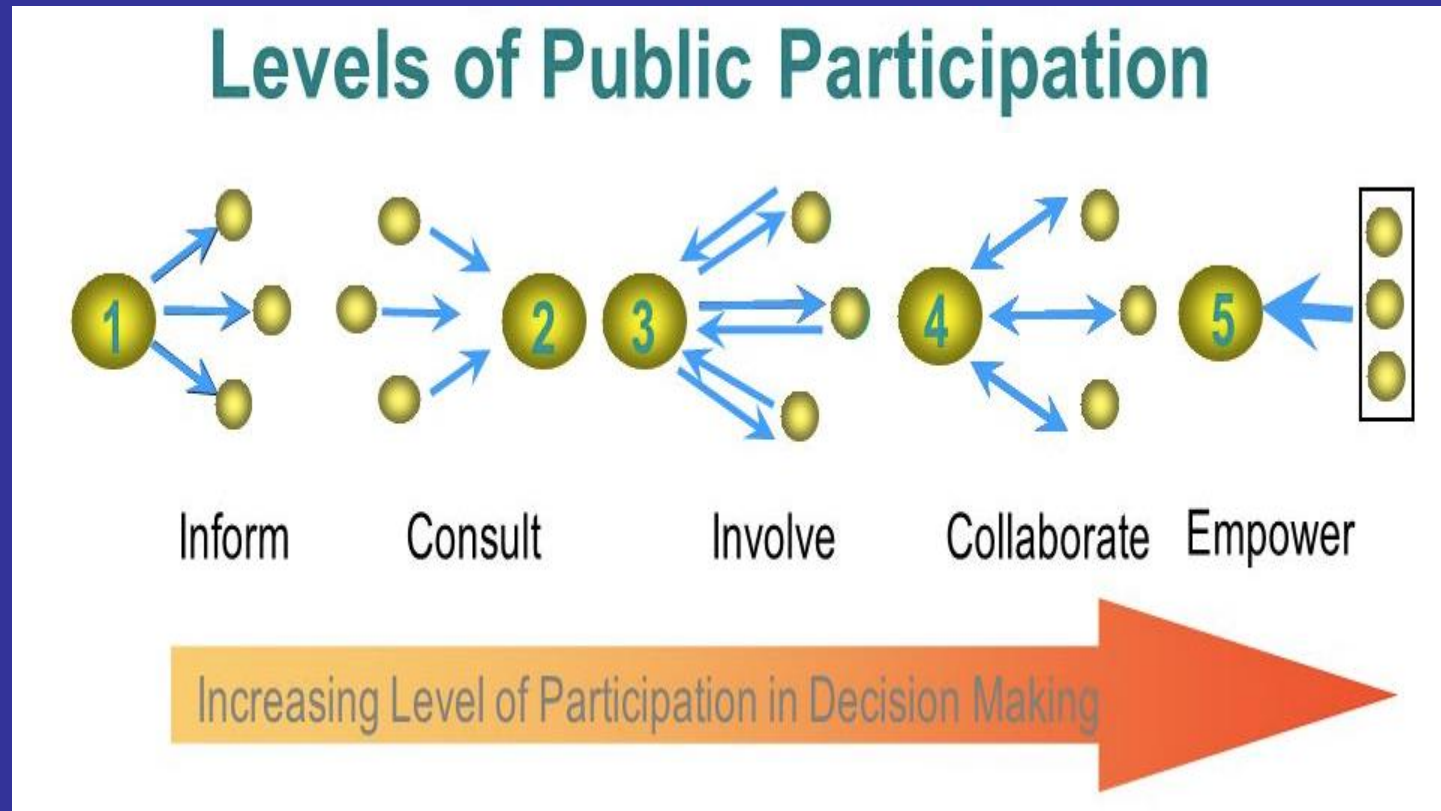


Increasing Level of Participation in Decision Making

# Citizen Participation level 4: Deciding together *what* to do (and doing it)



# Citizen Participation level 5: Citizens calling the shots – full power

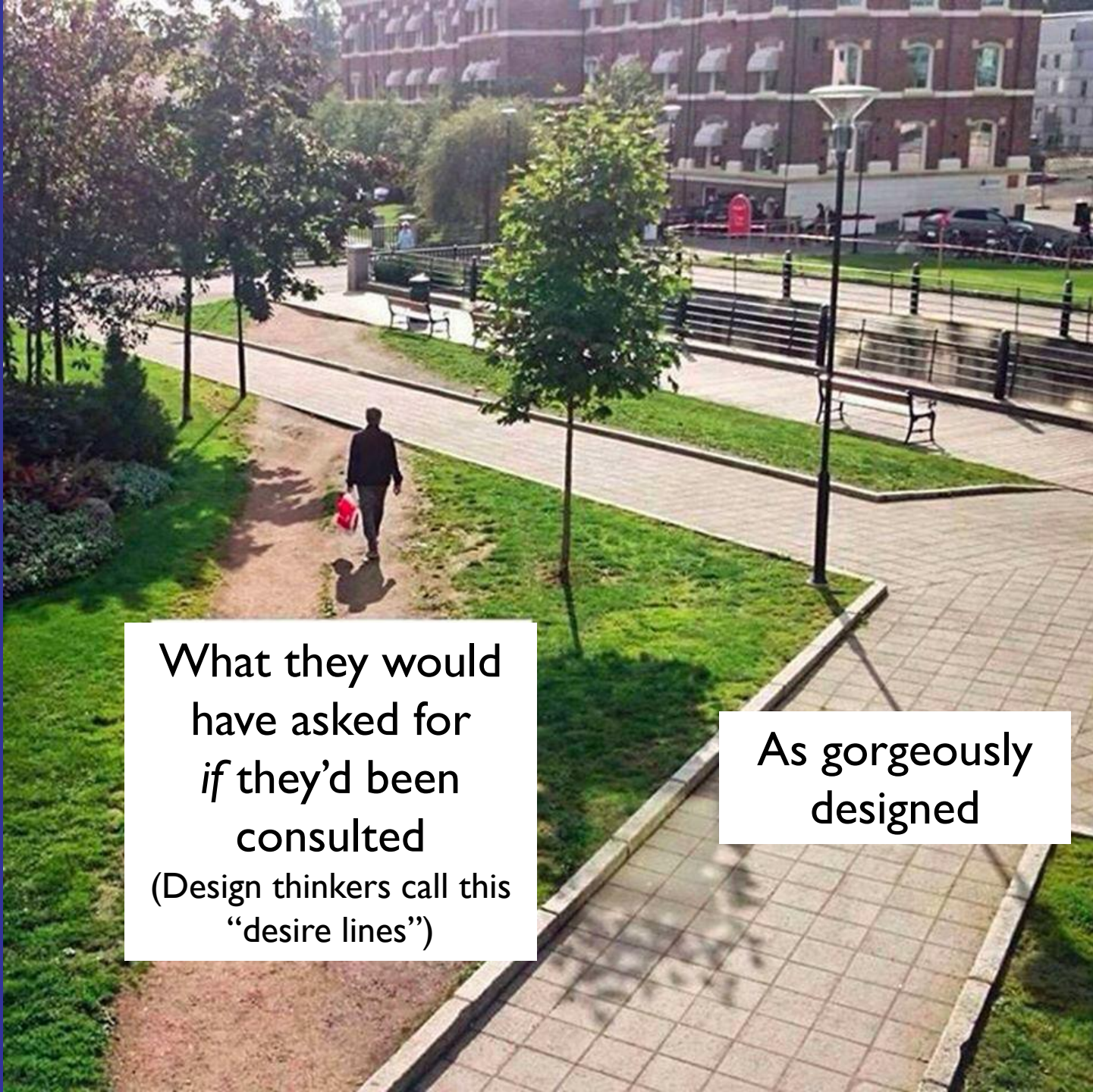




Example of “consult”:  
a sidewalk created  
before consulting  
the citizens.



As gorgeously  
designed



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

As gorgeously  
designed

# Moving up this ladder requires 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*

If we approach  
*the whole issue of  
treatment as being  
driven by the one who  
has the problem,*

# Compliance

(Whose goal is it, anyway?)

If we approach  
*the whole issue of*  
*treatment as being*  
driven by *the one who*  
*has the problem,*  
then sticking to the  
plan becomes  
*achievement, not*  
obedience.

**Achievement!**

~~Compliance~~

(Whose goal is it, anyway?)

**It's a true  
paradigm change**

# The Traditional Healthcare Universe



# Healthcare's "Copernican Shift"



*Copernican Shift*

**Microsoft**



**April 1967 (fifty years ago):  
“K. Switzer” runs the Boston Marathon**



# April 1967 (fifty years ago): “K. Switzer” runs the Boston Marathon



**“Get the hell  
out of my race!”**

# Remove constraints and the future changes

**1967**



# Remove constraints and the future changes

1967



1972



# Remove constraints and the future changes

1967



1972



1999



# Remove constraints and the future changes

1967



1972



2017



# Paradigm errors → wrong expectations

1967



1972



2017



*Next mental trap:*  
**“My patients  
aren’t asking  
for this.”**



*Vote NO*  
*on Woman Suffrage*

BECAUSE 90% of the women either do not want it, or *do not care*.

BECAUSE it means *competition* of women with men instead of *co-operation*.

BECAUSE 80% of the women eligible to vote are married and can only double or annul their husbands' votes.

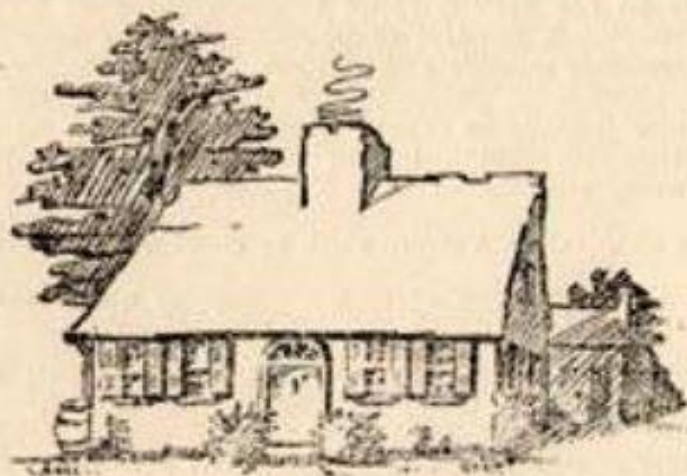
BECAUSE it can be of no benefit commensurate with the additional expense involved.

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.

*dupl*  
*Household Hints*

---



**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?

Vote NO  
on Woman Suffrage

*dupl*  
Household Hints



**BECAUSE 90% of the women either do not want it, or do not care.**

rate 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.

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Washington, D. C.

**Votes of Women can accomplish no more than votes of Men. Why waste time, energy and money, without result?**

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# Empowered, engaged, equipped, enabled: Enabling the power of e-patients

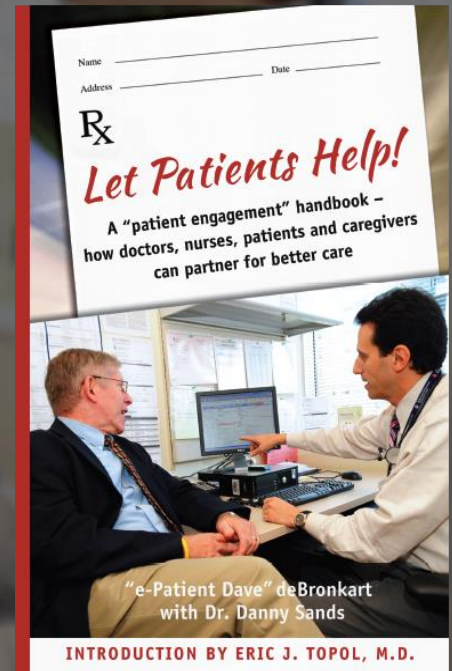
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dave@epatientdave.com



Bringing together e-patients and health care professionals.

# Question and Answer Session

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### Commission for Case Manager Certification

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# Thank you!

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- Please fill out the survey after today's session
- Those who signed up for continuing education will receive an evaluation from the Commission.
- A recording of today's webinar and slides will be available in one week at <http://ccmcertification.org>

