Empowered, engaged, equipped and enabled:

*Enabling the power of e-patients*

“e-Patient Dave” deBronkort
Patient Advocate and Activist

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

• Welcome and Introductions

• Learning Objectives

• Presentation:
  • MaryBeth Kurland, CAE
  • e-Patient Dave deBronkart

• Question and Answer Session
Audience Notes

• 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

• One continuing education credit is available for today’s webinar only to those who registered in advance and are participating today.
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

MaryBeth Kurland, CAE
Chief Executive Officer
Commission for Case Manager Certification
• Webinars
• Certification Workshops
• Issue Briefs
• Speaker’s Bureau
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

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

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

“e-Patient Dave” deBronkart

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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 founder
Tom Ferguson MD
1944-2006
Doc Tom said, “e-Patients are Equipped, Engaged, Empowered, Enabled.”
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.
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The Incidental Finding

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

“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)
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...
“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
“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
Surgery & Interleukin worked.
Target Lesion 1 – Left Upper Lobe

Baseline: 39x43 mm

50 weeks: 20x12 mm
ANALYSIS

Essay

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

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

- Immunology (including allergy)
- Screening (oncology)
- Urological cancer
- Urological surgery
- Urology
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Dave deBronkcart, policy adviser on patient engagement

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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
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.
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
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.

doi: 10.1370/afm.2036Ann Fam Med March/April 2017vol. 15 no. 2 158-161
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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
Citizen Participation level 1: “Here’s what we’re doing”

Levels of Public Participation

Inform

Increasing Level of Participation in Decision Making

http://staff.maxwell.syr.edu/cgerard/Fundamentals%20of%20Conflict%20Resolution/Slideshows/Public%20Policy%20Conflict.ppt
Citizen Participation level 2: “What do you think about what we’re doing?”

http://staff.maxwell.syr.edu/cgerard/Fundamentals%20of%20Conflict%20Resolution/Slideshows/Public%20Policy%20Conflict.ppt
Citizen Participation level 3:
Involving the public in your work

Levels of Public Participation

1. Inform
2. Consult
3. Involve

Increasing Level of Participation in Decision Making

http://staff.maxwell.syr.edu/cgerard/Fundamentals%20of%20Conflict%20Resolution/Slideshows/Public%20Policy%20Conflict.ppt
Citizen Participation level 4: Deciding together *what* to do (and doing it)
Citizen Participation level 5: Citizens calling the shots – full power

http://staff.maxwell.syr.edu/cgerard/Fundamentals%20of%20Conflict%20Resolution/Slideshows/Public%20Policy%20Conflict.ppt
Example of “consult”: a sidewalk created before consulting the citizens.
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 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.

(Whose goal is it, anyway?)
It’s a true paradigm change
The Traditional Healthcare Universe

Copernican Shift
Healthcare’s “Copernican Shift”
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
Remove constraints and the future changes

1967

1972

1999

Title IX

No person in the United States shall, on the basis of sex, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any education program or activity receiving Federal financial assistance....”

—June 23, 1972
Remove constraints and the future changes

1967

1972

2017

"No person in the United States shall, on the basis of sex, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any education program or activity receiving Federal financial assistance..."

—June 23, 1972
Paradigm errors $\rightarrow$ wrong expectations

1967

1972

2017

Title IX

Sports Illustrated

"No person in the United States shall, on the basis of sex, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any education program or activity receiving Federal financial assistance..."

— June 23, 1972
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 cooperation.

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.

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

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

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BECAUSE it is unwise to risk the good we already have for the evil which may occur.

Household Hints

Votes of Women can accomplish no more than votes of Men. Why waste time, energy and money, without result?
Let Patients Help: Summary
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- Participatory Medicine is empowered partnership
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- Environmental change alters what’s possible.
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- The current wave of health improvement is arising from sociology, not biology
Let Patients Help: Summary

• Participatory Medicine is empowered partnership

• Environmental change alters what’s possible.

• The current wave of health improvement is arising from sociology, not biology
  
  – Not everyone knows it. Be a leader.
Let Patients Help: Summary

- Participatory Medicine is empowered partnership
- Environmental change alters what’s possible.
- The current wave of health improvement is arising from sociology, not biology – Not everyone knows it. Be a leader.
- **Engagement in the medical record is good!**
Let Patients Help: Summary

• Participatory Medicine is empowered partnership

• Environmental change alters what’s possible.

• The current wave of health improvement is arising from sociology, not biology
  – Not everyone knows it. Be a leader.

• Engagement in the medical record is good!
Empowered, engaged, equipped, enabled: Enabling the power of e-patients

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Question and Answer Session

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www.ccmcertification.org
Thank you!

• 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://ccmccertification.org