



## IssueBrief

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# EMPOWERMENT

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

In January 2007, a routine shoulder x-ray revealed an unexpected grey smudge on Dave deBronkart's lung. More tests determined deBronkart had stage 4 kidney cancer. Tumors in his kidney, leg, arm, both lungs, skull and tongue confirmed the seriousness of his case.

"I was really sick," he says. "The best available data said that my median survival was 24 weeks after diagnosis."

deBronkart's next move was typical of the MIT grad. "I sure didn't want to overrule the physician trying to save my life, but by all means, I told my doctor, 'if there's anything I can do to help, let me know.'"

Surprisingly, deBronkart's primary care physician, Danny Sands, MD, recommended he visit an online patient community for cancer patients. "Yes, my doctor sent me to the Internet," he says.

deBronkart's story is a roadmap for patient empowerment and engagement—and the foundation for what has become his personal drive for

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PATIENT EMPOWERMENT  
ADVOCATE

***“There are very few consumer decision support tools available to those making health care purchasing decisions, and patients certainly can’t comparison shop by price and benefits like they’re accustomed to with other transactions.”***

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CEO, COMMISSION FOR CASE MANAGER CERTIFICATION

patient and caregiver involvement in care, or *participatory medicine*.<sup>1</sup> A firm believer that patients are the most underused resource in health care, deBronkart was empowered to confront his cancer with knowledge and peer support from the online patient community—and has spent the last decade encouraging others to do so, too.

## What is patient empowerment?

Although health care is the most important and costly purchase Americans make, “we don’t shop for health care the same way we shop for a car or a blender or for anything else that we buy online,” says MaryBeth Kurland, CEO of the Commission for Case Manager Certification. “There are very few consumer decision support tools available to those making health care purchasing decisions, and patients certainly can’t

comparison shop by price and benefits like they’re accustomed to with other transactions,” she says. And cost is certainly not the only concern when it comes to patient engagement and health. “Surveys show that patients would like to be engaged in their own care as well; however, they need to be empowered to do so.”

A self-professed “evangelist” for patient empowerment, deBronkart looks to sociology rather than medicine to shape a definition of the term. In 2002, the World Bank defined an empowerment framework in the context of poverty as “the expansion of assets and capabilities of poor people to participate in, negotiate with, influence, control, and hold accountable institutions that affect their lives.”<sup>2,3</sup> deBronkart adopts the organization’s working definition: “Increasing the capacity of individuals or groups to make choices (about

what they want) and to transform those choices into desired actions and outcomes.”<sup>4</sup>

Empowering patients to make those choices is often stymied by circumstances, culture and timing. A new diagnosis may come as a shock; when given a chance to ask questions of caregivers, patients don’t always react quickly with good questions, or probe providers for more information. Circumstances and culture also may prevent them from making informed decisions.

When providers do engage patients with information for them to make decisions, it’s often conveyed orally, or presented in unfamiliar terms. Studies show that between 40 and 80 percent of medical information provided by health care practitioners is forgotten immediately, and almost half of what is remembered is incorrect.<sup>5</sup>

So how should the health care system increase the capacity—and opportunity—for patients to make informed choices? By providing access to information they can understand in a variety of formats, deBronkart says, and by offering coaching to “increase their capacity” for being effective partners. “We know that if you give people timely, understandable guidance, they can be real

<sup>1</sup> “Participatory Medicine is a model of cooperative health care that seeks to achieve active involvement by patients, professionals, caregivers, and others across the continuum of care on all issues related to an individual’s health. Participatory medicine is an ethical approach to care that also holds promise to improve outcomes, reduce medical errors, increase patient satisfaction and improve the cost of care.” Society for Participatory Medicine, <http://participatorymedicine.org/>

<sup>2</sup> *Empowerment and poverty reduction: A Sourcebook*. World Bank, 2002. <http://documents.worldbank.org/curated/en/827431468765280211/pdf/multi0page.pdf>

<sup>3</sup> What is Empowerment? The World Bank. <http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTPOVERTY/EXTEMPOWERMENT/0,,contentMDK:20272299~pagePK:210058~piPK:210062~theSitePK:486411~isCURL:Y,00.html>

<sup>4</sup> The World Bank. Empowerment. <http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTPOVERTY/EXTEMPOWERMENT/0,,contentMDK:20245753~pagePK:210058~piPK:210062~theSitePK:486411,00.html>

<sup>5</sup> Kessels R. Patients’ memory for medical information. *J R Soc Med*. 2003 May; 96(5): 219–222. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC539473/>

contributors. These are new insights that are altering the progression of care by altering the balance of authority and power from providers to patients—through information, knowledge and increasing confidence.”

Offering access to information sources such as websites from trusted providers (e.g., Mayo Clinic's patient care and health information portal) is also a good place to start, he says, because patients can understand its plain language, clear and simple organization, and range of information.

## Collaborative care through shared and open medical records

Giving patients access to their medical providers' notes is also gaining ground as a means to both enhance accuracy and empower patients. A 12-month project funded by the Robert Wood Johnson Foundation, called OpenNotes, gave more than 19,000 patients access to their doctors' notes following visits to the doctor.<sup>6,7</sup> The original research found that more than four out of five patients read their notes, and of those who did, the vast majority said the experience made them feel more in control and helped them take medications as prescribed. At the end of the study, 99 percent of patients wanted the practice to continue, and no doctor elected to stop offering access.

<sup>6</sup> Robert Wood Johnson Foundation, OpenNotes Grants. <http://www.rwjf.org/en/how-we-work/grants/grantees/OpenNotes.html>

<sup>7</sup> OpenNotes. <https://www.opennotes.org>

The initiative was so successful that Geisinger Health Systems, a research participant, extended access to the OpenNotes model to more than 100,000 patients after the project was complete.<sup>8</sup>

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Further, the study proved that common misconceptions about making clinical notes available to patients—that it will increase worry and confusion or create additional work for doctors—were unfounded. Once they had access, patients said it is important to them; 85 percent reported having access to their doctors' notes would influence their choice of providers in the future.<sup>9</sup>

<sup>8</sup> Delbanco T, Walker J, Bell SK, Darer JD, Elmore JG, Farag N, et al. Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead. *Ann Intern Med.* 2012;157:461-470. <http://annals.org/aim/article/1363511/inviting-patients-read-doctors-notes-quasi-experimental-study-look-ahead>

<sup>9</sup> Robert Wood Johnson Foundation, “Geisinger Gives Patients Access to Doctors' Notes.” May 2013. <http://www.rwjf.org/en/library/articles-and-news/2013/05/geisinger-gives-patients-access-to-doctors-notes.html>

Patients in the study also tended to share their records with their caregivers. deBronkart says this is a step towards empowerment of family members, a cultural change that he is seeing grow. Opening the record to others, though, should be completely driven by the patient's own preferences.

“A big part of the work of case managers is to be attuned to the current capacities of your individual patients and their families—and to develop their capacity as time goes by,” he says. Some patients may want their families to have total access to their health records, but others may prefer to keep the information private, or to share it with only particular caregivers.

## Relevant information—from other patients

True empowerment requires a cooperative model of care that encourages and expects active engagement from health care providers, patients and their caregivers. In his own case, deBronkart said he was empowered with knowledge gained from 16 other patients who received the identical cancer treatment he did, high-dose interleukin-2. He found that community of patient peers on a chat site hosted by the Association of Cancer Online Resources<sup>10</sup>—the website recommended by Dr. Sands.

Insight from other patients was invaluable because there was no

<sup>10</sup> Most of ACOR now resides at <https://www.smartpatients.com>

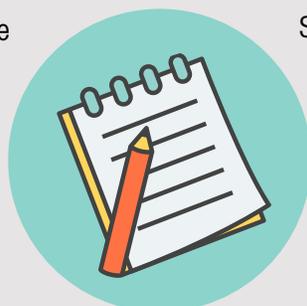
## The OpenNotes experiment: Access to records activates patients

More than 40 years ago, an article in the *New England Journal of Medicine* put forward a revolutionary proposal: “Four serious problems (maintaining high quality of care, establishing mutually satisfactory physician/patient relations, ensuring continuity and avoiding excessive bureaucracy) could be alleviated, in part, *if patients were given copies of their medical records* (emphasis added).”\*

It was the foundation for what would become a movement among health professionals, patient advocates and policymakers for not only improving access to patients to their own records, but also for shared decision making.

OpenNotes, a study funded by the Robert Wood Johnson Foundation, was launched in 2010 to test the idea. Beth Israel Deaconess Medical Center in Boston, Geisinger Health System in Pennsylvania, and Seattle’s Harborview Medical Center collaborated with 105 primary care doctors on the study, inviting 20,000 patients to read their notes via secure online portals. The year-long trial ended with significant findings.<sup>†</sup>

- 77 to 87 percent of patients across the three sites said OpenNotes helped them feel more in control of their care;
- 78 percent of patients said that OpenNotes helped them take their medications as prescribed;



- 99 percent of patients wanted OpenNotes to continue; and
- Not a single physician opted to stop OpenNotes. Few (0 to 5 percent, depending on institution) reported that patient access to notes led to longer visits or more time addressing patient questions outside of visits.

Since the study’s conclusion, both Beth Israel Deaconess Medical Center and Geisinger Health System have expanded access to OpenNotes, with more clinicians opting to share notes with patients. Beth Israel Deaconess also invited patients to view notes written by their psychotherapists.

Additional institutions, including Milwaukee’s Columbia St. Mary’s health system and the Department of Veterans Affairs, as well as a Northwest consortium of providers (Kaiser Permanente Northwest, Legacy Health, Oregon Health and Science University, the Portland Clinic, Salem Health, OCHIN, Providence Health System, Peace Health Medical Group and Samaritan Health Services) have adopted OpenNotes based on the results of this important research.

In 2017, more than 14 million patients in the US have access to their doctors’ notes. Ongoing research is underway on five continents and 11 countries to explore how offering patients access to their own records can enhance engagement and shared decision making.<sup>‡</sup>

\*Shenkin B, Warner D. Giving the Patient His Medical Record: A Proposal to Improve the System. *N Engl J Med* 1973; 289:688-692 September 27, 1973. <http://www.nejm.org/doi/pdf/10.1056/NEJM197309272891311>

† Delbanco T, Walker J, Bell SK, Darer JD, Elmore JG, Farag N, et al. Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead. *Ann Intern Med*. 2012;157:461-470.

‡ OpenNotes, Our history. <https://www.opennotes.org>

available literature for patients about how to cope with the drug's side effects. deBronkart tapped into their experience and gained not only compassion and real-world advice, but also vital information that affected his health outcome. Armed with this information, he recognized side effects when they hit and was often able to cope with them. Later, in an article printed in the *BMJ*, his oncologist said, "I don't know if you could have tolerated enough medicine if you hadn't been so prepared." Indeed, at one point his blood pressure dropped drastically and the clinicians discontinued his treatment early.<sup>11</sup> deBronkart's knowledge and awareness—gained from information shared by other patients like him—may have saved his life.

## Leveraging information from patients "like me"

"So here is the question for the scientific mind: How can it be that the most useful and relevant information can exist outside of the peer-reviewed literature where we are trained to look?" he asks.

The value of what can be learned from other patients and from online sources far outweighs the risk when it's used in collaboration with the medical team, he says. deBronkart is a strong advocate for bringing information that patients learn online to the care team to confirm its validity and appropriateness to their particular case.

<sup>11</sup> deBronkart D. How the e-patient community helped save my life: an essay by Dave deBronkart. *BMJ* 2013;346:f1990. <http://www.bmj.com/content/346/bmj.f1990>

"I wasn't trying to be the doctor. I was trying to be an information bloodhound," he says of his own experience.

deBronkart says that much of the anecdotal wisdom he gained from patients is still not covered by peer-reviewed literature, although his oncology team confirmed it was indeed accurate and actionable. Going online to learn more about your health care can work in your favor. "There is an additional, valid source of information out there. There's garbage amid the gold, so you have to work at it, but it's clinically accurate to say that patients

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PATIENT EMPOWERMENT ADVOCATE

can bring good information back to the treatment team," he says. Clinicians who dismiss patients that bring information they learn online to appointments are "unwittingly shutting off this potential new pathway of value." deBronkart points to the internet revolution and the vast quantity of patient-generated information available online, and the value of relationships that can

be made for ongoing support. It's a resource patients and caregivers should be encouraged to tap. "Information in medicine is like a nutrient. Connections between people online are like information capillaries that make it possible today for someone with no medical training to get their hands on good information."

## A workable model for patient engagement

Again, deBronkart looks outside medical research to identify a workable model for patient engagement: Arnstein's ladder of citizen participation.<sup>12</sup> He believes it is a model that can be useful as organizations work to build patient-centered approaches to care delivery.

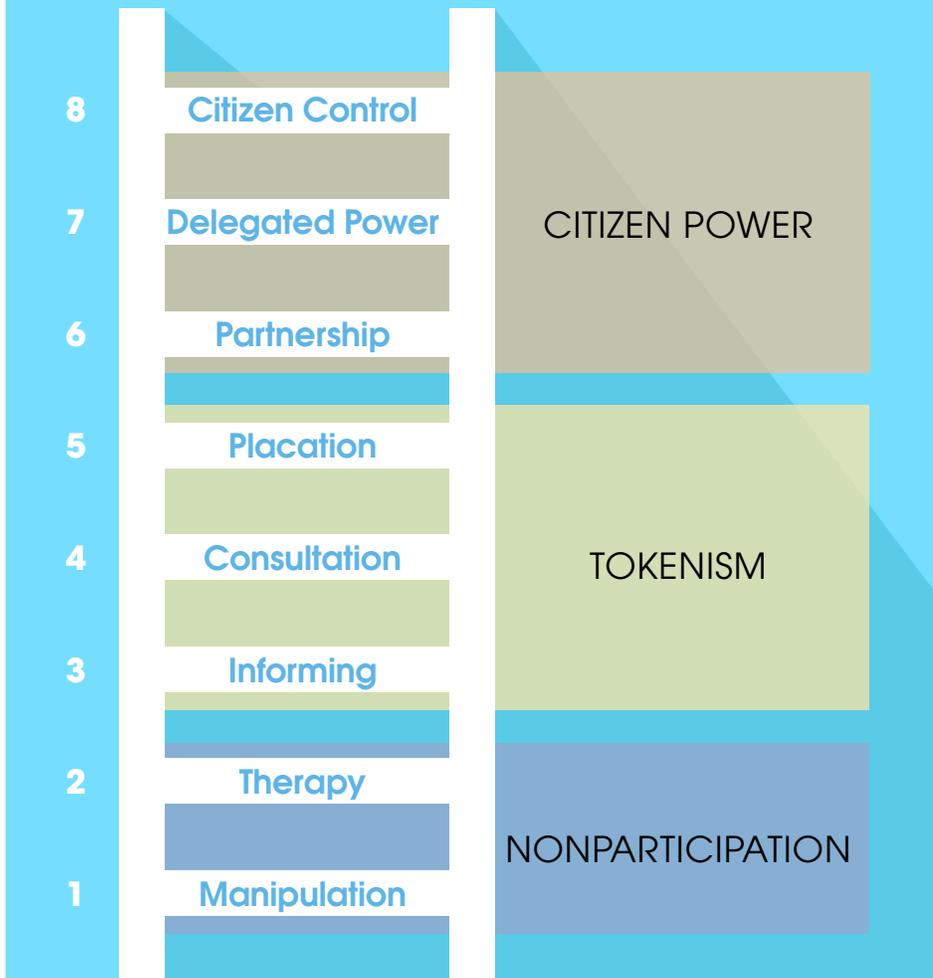
Arnstein's model originated as an evolutionary approach for citizen participation in urban planning. The goal is to evolve to the top of the ladder to truly tap into valuable insights from the citizens who are most affected by change. It includes three primary stages:

- nonparticipation as the lower rungs;
- tokenism for the middle rungs; and
- citizen power at the top.

Applied to health care, deBronkart says the lower rungs on the ladder—nonparticipation and tokenism—are merely a nod at engagement for the sake of show.

<sup>12</sup> Arnstein S. A Ladder of Citizen Participation. *Journal of the American Planning Association*, Vol. 35, No. 4, July 1969, pp. 216-224.

## Arnstein's Ladder of Citizen Participation



Arnstein S. A Ladder of Citizen Participation. *Journal of the American Planning Association*, Vol. 35, No. 4, July 1969, pp. 216-224.

empowerment and increasing people's capacity to engage," deBronkart says. "I can tell you first hand that there's a difference when we approach the whole idea of treatment as driven by the person who has the problem, because then 'compliance' turns into 'achievement.' If I have set the goal, then success is me, the patient, becoming autonomous and confident and having the life that I want."

### Citizen power: Patient activation as a goal, measurement as a tool

When patients are equipped with information and empowered through engagement, they're enabled as actors in their care. Patient activation—an individual's knowledge, skills and confidence related to self-management—is commonly measured in health care using a scale called the Patient Activation Measure (PAM).<sup>13</sup> Scored on a zero-to-100 scale, PAM reveals four levels of activation, from low (level one) to high (level four).

PAM has been used by health providers and in research for more than a decade to assess patients with complex health care needs. It supports patient activation as a powerful predictor for high resource utilization and health outcomes. Patients' ability to monitor conditions, follow treatment regimens and manage their own symptoms is likely to

<sup>13</sup> For a fundamental introduction to the PAM, see <http://www.slideboom.com/presentations/404469>

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"For example, with hospital patient advisory groups, they will commonly start out by bringing patients in, giving them milk and cookies and giving them a presentation about what they are doing. At the next level up, they may ask participants, 'what do you think about what we're doing?'"

"The climb up to the top of the engagement ladder requires

*It's a matter of nudging patients up the patient engagement ladder, one rung at a time, freeing individuals from the constraints that prevent them from acting in their own best interests.*

determine whether they will need costly care in the future.<sup>14</sup>

“Using a few questions, clinicians and case managers can assess whether somebody believes they can do anything useful for themselves or not—that’s PAM level one. At level two, they believe they could, but they haven’t started yet. At level three, they’ve taken action, and at level four they’re confident. The research around using the PAM has documented how you should speak differently to people at the different levels, because activation is progressive. You don’t jump from level one to four. The job is to move the patient up to the next level, to really coach them up the ladder.”

## Case managers as capacity builders

In terms of individual patients, the goal for case managers is to help patients become true, contributing

partners with other members of the care team. It’s a matter of nudging patients up the patient engagement ladder, one rung at a time, freeing individuals from the constraints that prevent them from acting in their own best interests.

At times patients will be more empowered and activated on their own, but at other times the clinician or case manager may need to act as the driver for greater patient engagement. “You need to be sensitive to where each individual is on the trajectory of motivation and change,” deBronkart says.

He cautions against the notion that patients and families don’t want to be engaged, just because they aren’t asking for empowerment and activation.

“Go back to the presidential election of 1912. At the time, there was a vote on whether women should

get the vote, and the number one reason against giving it was that 90 percent of women weren’t asking for it. You see, that is the disconnect with patient empowerment, too: If you have a wrong paradigm—women don’t want to vote, or patients don’t want to be empowered—you’ll get a wrong expectation.”

deBronkart recommends opening the door to engagement by asking patients whether they would like to explore more information, and then offering resources to help. “That keeps the authority, the power, if you will, in the hands of the person who has the problem. If they say yes, that becomes the foundation for working together to assess their capacity and expand it. And that’s truly patient-centered, as it should be.”

For case managers, patient engagement is a critical part of the process, Kurland says.

“The case manager can look at ways to proactively invite patients and their caregivers to do their own research on the resources and tools that they can tap into. Case managers are advocates and can help make it clear: Patients, ultimately, are in charge of their own health. Case managers can help liberate them and offer guidance they need to work as partners in their care and drive their own health advancement.” ■

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<sup>14</sup> Hibbard J, Greene J, Sacks R, Overton V, et al. Adding A Measure Of Patient Self-Management Capability To Risk Assessment Can Improve Prediction Of High Costs. *Health Aff* March 2016 vol. 35 no. 3 489-494. <http://content.healthaffairs.org/content/35/3/489.full?sid=315f58fe-2b82-4b32-b5c1-ccd07c4d7eef>

## About the Experts



**Dave deBronkart  
(e-Patient Dave)  
Patient Empowerment Advocate**



**MaryBeth Kurland, CAE  
CEO, Commission for  
Case Manager Certification**

Dave deBronkart, known on the internet as e-Patient Dave, is the author of *Let Patients Help: A Patient Engagement Handbook* and one of the world's leading advocates for patient engagement. After beating stage 4 kidney cancer in 2007 he became a blogger, health policy advisor and international keynote speaker. An accomplished speaker in his professional life before cancer, he is today the best-known spokesman for the patient engagement movement.

deBronkart has appeared in *Time*, *US News*, *USA Today*, *Wired*, *MIT Technology Review*, and in the *HealthLeaders* cover story "Patient of the Future." His writings have been published in the *British Medical Journal*, the *Society for General Internal Medicine Forum*, *iHealthBeat*, and the conference journal of the American Society for Clinical Oncology. He serves on the *British Medical Journal's* patient advisory panel, and he was the Mayo Clinic's 2015 visiting professor in internal medicine.

MaryBeth Kurland leads and sets the Commission's strategic mission and vision, manages relationships with likeminded organizations and oversees business development as well as the organization's programs, products and services. She works directly with the Board of Commissioners, building its corps of volunteer and subject matter experts that directly support and evaluate certification and related services. Prior to becoming CEO, Kurland served as the Commission's chief operations officer, and served as staff lead for the development and launch of the Commission's signature conference, the CCMC New World Symposium.

Kurland brings extensive experience to her role, having served as executive director of organizations including the Association of Medical Media, Office Business Center Association International and the League of Professional System Administrators. She holds a bachelor of arts from the University of Delaware and is a member of the Institute for Credentialing Excellence, the American Society of Association Executives, and the Mid-Atlantic Society of Association Executives. In 2011, Kurland was recognized as Association TRENDS Young & Aspiring Association Professional.



### Commission for Case Manager Certification

1120 Route 73, Suite 200 • Mount Laurel, NJ 08054  
(856) 380-6836 • [ccmchq@ccmcertification.org](mailto:ccmchq@ccmcertification.org)  
[www.ccmcertification.org](http://www.ccmcertification.org)

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