

# POSTS MADE IN SEPTEMBER 2012

## WHO'S IN CHARGE?

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As a patient, do you consider yourself to be in charge of your health care? Do you take the initiative to schedule your appointments, get your screenings and ask the right questions when you see your doctors or nurses? Do you make sure that you are getting your flu shot?

Do you keep a record of your immunizations, medications, procedures and family history so that you show up with your complete health information at the point of care? Are you one of those patients who goes online to research your health conditions, seek information and look for communities to discuss health issues?

Who do you blame for being overweight? Do you blame yourself for eating the wrong foods and too much of them, or your doctor for not giving you the proper advice about nutrition?

Who do you feel is at fault when you do not comply with a medication regiment that the doctor has prescribed, the doctor or pharmacist for not explaining all of the significant details about the medication or yourself for failing to adhere?

Are you an engaged patient or are you a passive recipient of health care?

Patient engagement has been receiving serious attention. Recent healthcare legislation mandates that patients must be engaged. Meaningful Use Stage II that will go into effect in 2014 outlines four patient engagement criteria:

(1) You must have access to an electronic copy of your health information

(2) You must receive clinical summaries of all office visits with your physician within three days of the visit regardless of whether or not you request, or want this information. The summaries may be given to you on a CD, via secure email or a secure online portal, on a USB drive or in a printed copy

(3) Your physicians must send you reminders about preventive follow-up care and appointment recalls.

(4) You must have timely electronic access to your health information within four business days of that information being updated in your electronic health record.

Patient engagement has been acclaimed by some as the Holy Grail in physician/patient relationships today. Clearly it requires effort on the part of both the patient and the physician/physician assistant/nurse practitioner.

One of my colleagues in the Society of Participatory Medicine, advocates that health coaching, focused on helping people gain the knowledge, skills and confidence to become active participants in their care is the way to increasing patient engagement. The idea of attending a workshop to learn skills in order to become an engaged patient is a bit too much for many of us. However, it takes concerted effort and knowledge to take charge of your health care.

At the end of the day it is up to each of us to make that commitment, to foster a trusted relationship with a health care provider and to truly engage in health care choices and decisions.

**[BLUE BUTTON: PROVIDING PATIENTS WITH ACCESS TO THEIR DATA. DOES IT WORK?](#)**

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There is an intriguing program dubbed Blue Button® that was launched by the Obama administration in 2010 to enable individuals to download their personal health information as an ASCII text file directly to their computers, mobile devices and tablets. The idea of Blue Button is to provide individuals with their specific health data in a readable format so that they can use it and share it with their providers and care planners. Blue Button data also helps physicians rapidly understand the health status of a new patient and quickly evaluate recent treatment. The idea is viable, in concept, but for it to be effective it has to work for all users transparently.

Blue Button ties directly into a key component of Stage II Meaningful Use of electronic health records which says that patients must be able to download, view and have access to their health information within four days of when that information was generated or within 36 hours after a hospital discharge. However, before there is broader use and acceptance of Blue Button, millions of health care consumers in U.S. need to be educated about why having health data in their own hands is important. They also need to understand what they can do with that information. Finally, they need easy access to Blue Button.

[http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/Stage2Overview\\_Tipsheet.pdf](http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/Stage2Overview_Tipsheet.pdf)

A Markle Foundation Survey on Health in *Networked Life*, Jan 31, 2011, indicated that roughly two in three individuals, as well as most doctors, agree that people should be able to download their personal health information.

<http://www.markle.org/publications/1441-public-and-doctors-alike-support-allowing-individuals-download-their-own-health-in>

A goal of the Office of the National Coordinator for Health IT is to move the bar from the current one million users of Blue Button, to ten

million and eventually to all citizens. Currently, over 500,000 veterans are using the Blue Button program that is available on their laptops, tablets and even their mobile phones to download data including appointment information, prescriptions and medications, laboratory results, vital signs and readings, military health history and military occupations. They access this health information on the MyHealtheVet patient portal, click the Blue Button on the portal and download or print their health records for the purpose of sharing them with doctors and other health providers.

Medicare launched its own version of Blue Button in September 2010 on the My Medicare portal theoretically giving 40 million beneficiaries access to their Medicare claims forms. There are two problems here: (1) most Medicare beneficiaries have never heard of Blue Button and (2) it is not easy to use. I personally went to the [mymedicare.gov](http://mymedicare.gov) site, signed in and tried to press the Blue Button to download my data twice and nothing happened.

Blue Button is also available to users of Microsoft Health Vault and Dossia as well as Aetna, Kaiser Permanente, and McKesson, all of whom offer patient-controlled personal health records. Once again when I tried to click on the Blue Button to download my data in Microsoft Health Vault, it did not work and asked me for a veteran identification. I am not a veteran.

The goals of Blue button: (1) Give consumers **Access** to health information (2) catalyze market innovation to allow consumers to take **Action** toward better health using health information; and (3) shift consumer and provider **Attitudes** in support of consumer engagement in health are admirable. But we have to ask:

Are patients clamoring for their personal health data?

Are patients going to know what to do with their data?

Do we not need extensive education programs behind the Blue Button initiative?

Are physicians going to work with their patients to attain better communication and cooperation once patients have their data?

Is this just another example of the system forcing a program on the American public that people do not want, do not understand, or are oblivious to?

Let's hope not. As e-Patients many of us do want to have our personal health data downloaded to our computers or other devices. We want to be able to easily access our health information at the point of care so it can be shared with our providers. However, the launch of this program requires training and communication that seems to be missing.

### [HOW DO PATIENTS MAKE GOOD CHOICES?](#)

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When you go to the supermarket, it is fairly easy to make a good choices about which cereal or fruit to purchase. At the paint store there are a lot of colors to choose from, but you generally can make a decision after a bit of deliberation. When you choose a new automobile, you make an informed decision based on certain preferences such as size, color, style or brand and parameters such as price and performance. This is information that you get from research, reading articles and checking ratings.

When it comes to medical decisions, you used to leave the choice of treatment entirely in the hands of your doctors. Although these decision are often life-altering, it is now up you or your families to choose which way to treat your medical issues. This change has occurred because for many conditions: (1) There are no clear-cut parameters with proven success; (2) The medical experts differ

regarding the best way; and (3) Although there is an abundance of information about medical issues, that information is often difficult to comprehend.

A recent letter to the editor in the [New York Times](#) related the story of a patient who was undergoing cancer treatment. The doctor suggested that she have a feeding tube inserted during the treatment. The doctor explained the benefits and the risks but left the decision to the patient. Initially she refused, but over time she realized this was a bad decision and finally after becoming too weak to continue her treatment accepted the tube and completed the treatment. This illustration points out the difficulties we all face when forced to make choices regarding the treatment for health issues.

Let's take **Prostate Cancer** as an example. How does a patient make a choice of treatment among the three approaches, all of which are acceptable by medical authorities, to treat early stage prostate cancer:

**Active surveillance** – Wait and see what develops with close monitoring by your physician, including frequent blood tests and biopsies

**Surgery** – Usually recommended for individuals younger than 70 who are in good health. The strategy is to remove the prostate, realizing that there may be side effects and radiation may follow.

**Radiation Therapy** – Recommended for men of any age with early stage prostate cancer, particularly for individuals who have health concerns, and therefore who are not good candidates for surgery, and for individuals who have had surgery and need further treatment.

<http://www.cancer.gov/cancertopics/treatment/prostate>

How about the choices patients who have [multiple coronary artery blockages](#) have to make? There is the question of whether stents or coronary bypass surgery is the right answer. Although many studies

have been done, there is not enough definitive evidence that shows better survival benefit from coronary bypass over stents. Additionally, many patients with coronary artery disease do just as well with medication as with either procedure, both of which are invasive.

<http://heartdisease.about.com/od/angioplastystents/a/sos.htm>

Many patients who need a [hip replacement](#) do not even realize that there are choices. These include:

**Total hip replacement;** where both the thigh bone (femur) and the socket are replaced with synthetic implant materials

**Partial resurfacing,** the most bone-conserving approach to hip surgery, where only the femoral head (where the leg joins the hip) is reshaped and resurfaced and the hip socket (acetabulum) is left completely intact. The benefit with resurfacing is that the patient keeps most of his or her own bone, which allows for easier revisions in the future (if one becomes necessary). These differences could mean improved outcome, smaller incisions that heal faster, less blood loss and shorter hospital stays.

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Perhaps the most difficult choices are those involving medications. Whether to take medication for certain conditions such as diabetes and hypertension or change your diet and lifestyle are dilemmas that many individuals face. There are also complicated choices to make when deciding with whether or not to do hormone treatment that can have severe side effects.

In all of these situations, weighing the risk/benefit is not easy. What can patients do to help them make these decisions:

Proactively do your research including: reading articles, talking with friends and family, seeking reputable online communities who have similar conditions, and questioning members of the community regarding their experiences so you understand your options;

Engage in a consultative, in-depth discussion with your doctor.

If there is still doubt in your mind seek a second, even a third opinion from other qualified physicians. Once you have all the information you can possibly put together to make an intelligent decision create a chart listing all of the risks, benefits, side effects, and contingencies. If you still have questions, consult your doctor once again because in a trusting partnership with your physician, you should be able to come to the best conclusion for your particular circumstance.