

POSTS MADE IN OCTOBER 2012

[SOCIAL NETWORKS DRIVE PATIENT COLLABORATION](#)

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When people have questions, problems, and issues related to health conditions they generally turn to friends, colleagues, neighbors or to online communities where they can find sympathetic listeners and information resources to address their concerns. These health social networks bring together people with shared interests to interact, answer questions and just be there to support one another.

A key value of health social networks is that they are patient driven. They supplement and extend traditional health delivery systems that we are all accustomed to. They are composed of a community of individuals who share information, symptoms, and treatments, by leveraging the collective experiences of the group.

As a result, patients who go to social network sites become empowered and engaged, even as they find comfort and solace. I recently joined a breast cancer social network, **My Breast Cancer Team (MYBCTTeam)** where I have been able to get informative details about the after effects of radiation therapy and the potential side effects of tamoxifen, directly from the personal experience of several individuals. This is not the same as checking studies or talking with my oncologist, who I totally respect and trust.

A survey of 1,060 U.S. adults by the PsC Health Research Institute found that a third of the respondents are gravitating to social networks for health care discussions. Their attraction is that they believe this is a good way to manage their health.

<http://www.ama-assn.org/amednews/2012/04/30/bisa0430.htm>

On health social networks, patients can access services ranging from basic emotional support that comes from talking to individuals who are going through similar issues, to helpful information about procedures, treatment choices, medications and side effects. This information usually is vetted by credible physicians who join these networks and are willing to answer questions. Some social networks also offer tools for monitoring and managing chronic conditions. Others provide cutting edge information on results of clinical trials that may be a last resort.

A list of the most popular social networks for health care includes:

Patients Like Me: a community that enables people to share information and data on treatment, medications, and outcomes so that they can make choices based on real-world experiences of other patients with similar issues. Patients Like Me has grown to over 167,500 patients and more than 1,000 conditions.

Inspire: a high engagement peer-to-peer network with many communities of individuals who discuss a variety of issues around diseases. Inspire includes over 275,000 total members, over 50,000 of whom have various types of cancer. These individuals post their thoughts and answer the questions that their peers raise about their disease.

Daily Strength: a comprehensive health network of people who share advice, treatment experiences and support with over 500 individual support groups. Daily Strength offers research on the latest drugs and treatments as well as alternative medicine. This site includes advice, articles, from medical professionals and health experts.

MyFamilyHealth: a social community that allows patients to connect with their relatives and family members to record and track their family health history.

Revolution Health: an online health and medical information and networking site that offers tools aimed at helping individuals by urging them to ask questions and answer other users' questions, rate their doctors, participate in online discussions and personally contribute content. The site also has a number of tools(apps) to help people become healthier.

Some tips and guidelines for using social networks to assist you with health issues:

Do not believe everything you read on a social network. Be aware that these sites are not monitored or regulated and are only as valuable as the correctness of the opinions expressed. As a result you should always verify information with your own providers before implementing suggestions or ideas that you pick up.

Determine what you want to get from a social network.

Learn how to navigate the site so you can seek out specific people who will be most helpful to you.

Selectively participate in the conversations and share information so that others will share with you. Only reveal what you are comfortable discussing.

Do not get bogged down with too many social networks. Choose the one that is most relevant for your specific health situation.

COLLABORATIVE TEAMS THAT INCLUDE PATIENTS MAKE CARE COORDINATION

POSSIBLE

2 Replies

Care coordination requires that the right information reaches the right people within an optimal time frame, so that a patient's full information is always at the point of care, and all of the follow-up clinical work, as well as the claims processing behind it, is in place.

This system works pretty well in a contained health care setting such as Kaiser Permanente, the VA or Group Health in Seattle, that has an established digital health record, a viable patient portal and a committed patient population that works with their providers to insure their care coordination.

For the rest of the health institutions and group practices in this country that are not in a contained health care setting, care coordination is difficult at best. There is no question that electronic health records, patient portals and health information exchange that provide access to patient information are critical for care coordination.

Although these are in place in many practices; absent in many others, it is not enough. There has to be a culture of cooperation between physicians and patients that is often missing.

Today, communication of orders for care, health histories, lab results, treatment information, medications, allergies and other vital data are often missing when the patient arrives to receive care.

How can that change?

(1) By having the tools for collaborative exchange of information in place. With cloud computing there are no longer bandwidth restrictions for enabling these technologies, although the costs have to come

down. Even with the tools in place, there has to be the desire on the part of all of the stakeholders in the provider community – primary care physicians, specialists, hospital administrators, pharmacists, labs, payers, and patients – to work together to address this problem and take appropriate actions to make it happen.

(2) By involving patients, encouraging them to establish personal health records, and enabling them to assume some of the responsibility for bringing their information needed at the point of care with them so that it is available when they seek care. There are three distinct configurations available to individuals who want to establish personal health records:

(a) Stand alone data repositories that enable patients to create their own personal health record, and store and maintain it on a secure web site (e.g. WebMD and Revolution Health).

(b) Tethered systems that are an extension of an individual's provider health record which the individual can access through a portal. (e.g. PHRs created at a payer's web site)

(3) Interconnected PHR, an external repository of an individual's health data created by the individual (e.g. Microsoft Health Vault or Dossia).

We cannot assume that patients are going to remain passive recipients of health care, leaving it to their providers to worry about coordination of care. Patients can, and must become part of the team that is managing their health. They must take positive actions to assume control over their health information so care coordination will become a reality and patients will receive better quality, safer health care.

[OPEN NOTES: NEW BEGINNINGS FOR PATIENT ENGAGEMENT](#)

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In January I wrote a post about a study funded by the Robert Wood Johnson Foundation that was looking at physician and patient reaction to a program that enables patients to access their doctor's notes recorded during an office visit and stored in the electronic health record. The objective of the study was to evaluate the effect on doctors and patients of providing patients with access to these notes using secure patient portals.

The study included 105 primary care physicians, and 13,564 of their patients at three locations: the Beth Israel Deaconess Hospital in Boston, MA, Geisinger Health System in Pennsylvania and Harborview Medical Center in Seattle Washington.

The results, reported this week in the [Annals of Internal Medicine](#), indicate that of a total of 13,564 participants, 11,797 opened at least one note; 77-87% of them reported that open notes made them feel more in control of their care; and 60-78% reported increased medication compliance with the availability of the notes. A small percentage, 1-8% reported that the availability of notes caused them to feel confused and worried. Additionally, almost 90% believed that having these notes affected their decisions when seeking care in the future.

In other words, on an overall basis, this study proved that a majority of patients like access to their primary care physician's notes and will use them to increase their understanding of their health issues. Engaging these patients in this way will impact their quality of care. Furthermore, physicians who had been concerned that access to notes would cause patients to become worried realized that this only happened in rare instances. They also learned from the study that patient access to notes ended up having far less impact on the physician's time than they had anticipated.

For Open Notes to work there has to be a secure way to transmit information to the patient. In the case of the three institutions involved in the research, they all had a secure patient portal through which the notes could be accessed by patients. However, patient portals are not ubiquitous and will not be for some time, as they are costly to implement and maintain, particularly for small group practices and community hospitals that comprise the bulk of our medical delivery system in this country.

Although it is possible for doctors to produce patient notes on various media from old-fashioned paper to CDs and flash drives, this puts an added burden on the physician's office. However, doctors may not have a choice about providing notes in the near term as one of the mandates of Meaningful Use of Electronic Health Records, Stage 2 clearly states that by 2014, all physicians must provide patients with: (1) a copy of their electronic health record; (2) clinical summaries of their office visit (3) appointment recalls; and (4) timely access to health information.

The completion of this study reinforces that Open Notes promotes the type of patient/physician relationship that furthers patient engagement and empowerment and ultimately will help improve the health of patients, increase medication adherence and hopefully bring more efficiency into the health care system by reducing unnecessary office and ER visits.