

Insights

A collection of unique perspectives and valuable insights from a variety of stakeholders all deeply passionate about patient engagement and communication.

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Insights

I was thrust into the role of caregiver when my teenage son Zachary was diagnosed with a terminal brain tumor. Of course, it's a role no parent wants and my first thoughts were strictly focused on the fact that my once healthy son was likely going to be killed by a brain tumor. Our new reality was frightening, uncharted territory, and I wasn't at all prepared for everything that comes with being the caregiver of a very sick patient.

My husband and I were immediately overwhelmed by new medical terminology and the stress of making a decision regarding in which clinical trial to enroll Zach. We were frequently stressed and overwhelmed with the tasks we faced, including communicating effectively with a growing team of doctors, and caring for an increasingly sick child.

It didn't take long for us to realize that the adage "you don't know what you don't know" really plays a role while navigating an illness. Many times we asked ourselves why we weren't told something sooner, or why it took us so long to figure something out.

After Zach died, I became a passionate patient advocate determined to help others navigate their own medical journeys. I have learned that while most people struggle with managing illnesses and injuries, many don't realize how much they are struggling. Research has shown that patients don't remember 40-80% of what they hear at appointments, and of what they do recall, as much as half is remembered incorrectly. More than 50% of Americans are not taking their medication as prescribed. And all these misunderstandings, mistakes and misremembering have devastating consequences for all involved.

In order for patients to have the best outcome possible, it is vitally important that patients, and their family caregivers, be fully engaged in the process of their care. Those who communicate well with their doctors have improved outcomes. The problem is most people don't know how to be an effective member of their medical team, or they assume they are doing a better job of managing than they are.

The following content provides insights from a variety of stakeholders – representatives from insurers, benefits experts, a physician and a patient – all deeply passionate about patient engagement and communication. I believe that we can make big strides in improving patient communication and reducing risks related to medical errors, and I'm confident that we can make even bigger strides if we work together.

Roberta Carson
FOUNDER AND PRESIDENT, ZAGGO, INC.

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Insights

Phil Litos

PRESIDENT, HEALTH & BENEFITS

Marsh & McLennan Agency | New England

Phil brings more than thirty years of executive level management experience in the health benefits industry to his role as Chief Operating Officer, New England Region for Marsh & McLennan Agency. Phil began his career with Blue Cross and Blue Shield of Massachusetts and, during his tenure of more than two decades there, held a variety of senior positions, including Vice President Sales and Service. Phil is also a member of the New England Council's Health Care Committee and the Cystic Fibrosis Foundation's Uncork the Cure Committee's Event Co-Chair.

How have disease management programs changed over the years?

The earliest disease management programs started with pharmaceutical companies who identified patients with chronic disease and offered educational services to them. The goal was to educate the patient about his/her disease and increase compliance with their medication regimen; it wasn't until later that health plans began to implement in-house disease management programs directly followed by independent vendors. Employers and insurers were initially uncertain about investing and implementing disease management programs due to the lack of evidence that these programs actually helped contain cost, however, by 2005 more than half of insured U.S. workers were members of a health plan that offered at least one disease management program. Disease management programs have grown from offering only programs for their most prevalent chronic conditions to a longer list of programs for a variety of conditions. In addition to the disease specific programs, health plans and private vendors offer case management for higher cost and more complex cases, along with wellness and incentive programs to help consumers make better choices and improve their overall health status. These programs have also evolved to include more strategic outreach methodology, engaging technology platforms, and better metrics to track efficacy.

What benefits have you seen from disease management programs?

One of the main concerns with disease management programs is determining if the programs will save money and positively impact the health of a population. It is important, prior to implementing any type of disease management program, that data is used to identify the metrics you will track year-over-year to identify any cost savings or improved health status of the participating population. We have a client who has had great success with a comprehensive health management program, inclusive of disease management. This client had a high participation rate in the overall program, movement from high to medium risk for 47% of the population, and decreased premiums year over year.

What steps can employers take to continue to improve these programs?

Employers can consistently improve their disease management offerings by requesting regular data from their carrier or broker to identify the population of individuals suffering from chronic conditions, inquiring as to how these individuals are being managed by their chosen disease management program, and choosing metrics to help identify actual savings and new care gaps. Factors that should be considered to increase traction within the disease management program include: strategic marketing and general awareness that the program(s) exists, ease of access and cost for the members, incentives for participation, and commitment to protecting personal health information. Successful programs are those that can not only be measured, but those that members are eager to engage in and trust as well.

Christel Marchand Aprigliano is a powerful advocate for the diabetes community. Diagnosed with Type 1 diabetes in 1983, she founded The Diabetes Collective, Inc. which provides peer support idea exchange events for adults with diabetes (The Diabetes UnConference). She is also the co-founder of the Diabetes Patient Advocacy Coalition, a non-partisan non-profit organization focused on federal and state policy advocacy and awareness. She holds an appointed position on Florida's Diabetes Advisory Council, writes about diabetes at ThePerfectD, and is a popular public speaker on patient engagement and chronic illness management.

Can you describe how overwhelmed/stressed you feel dealing with your condition?

Diabetes is 24/7/365 with no breaks or time off for good behavior. Everything that I ingest, do, or feel can impact my overall health. As positive as I am about my diabetes management, it can be stressful and frustrating when you are dealing with multiple medications, medical professionals, and data. A chronic illness is a second full-time job.

Can you describe any positive and/or negative interactions with your doctors or other medical professionals?

I've had medical professionals who made assumptions, rather than listen to my symptoms. Those relationships didn't last long. I currently have a medical team who talks with me, rather than at me, making my chronic illness management more of a relationship than a program that must be followed without question.

What would you change about the way physicians and patients interact?

I would encourage patients to truly prepare for an appointment:

- Do research on your condition and what the latest treatments could be.
- Read patient stories about their experiences for your condition.
- Prepare a list of questions to go over and required prescription refills needed.

- Ask about clinical trials.
- Bring labs and notes from other physicians.
- Be succinct and time conscious. (Nobody likes to wait. Don't make the next patient wait because you weren't prepared.)
- If you do not prepare for an appointment, don't expect the physician to be a mind reader. They want to help you, but you have to tell them what you need.

Conversely, it would be great if doctors could:

- Be open and willing to do additional research on the patient's condition and/or refer the patient to a specialist.
- Empower staff to keep patients informed regarding wait times while in the waiting and exam rooms.
- Ask the patient how they are feeling emotionally, not just physically. Then truly listen to, and act on, the response.
- Provide online resources for patients to get trusted, factual information about their condition or illness. It's hard for patients to take in large amounts of medical information in one sitting, and some patients want access to additional information.
- Ask the patient about their prescription or healthcare coverage before prescribing medications, treatments and procedures. Prescribing medications or services that are cost-prohibitive severely reduces the likelihood of adherence.

Dr. Chris Landon is a pulmonologist with more than 30 years of experience in cystic fibrosis care related research, and the CEO of the Landon Pediatric Foundation.

Although we have made some progress in patient engagement, there is still a long way to go. What change do you think would have the most impact? If you could change one thing today, what would you change?

Clinicians are facing mounting pressures today; among them, less face-time with patients. Time spent with a patient during his/her annual well visit is often limited to 15 minutes – which is hardly enough time to adequately discuss a concern or moderate to severe health issue. Most of us got into medicine not to manage paperwork or complete EHRs, but to help the sick get better and help the healthy stay that way. I think a lot can be done to improve physician-patient engagement – and it starts with having the time to discuss a patient's concerns and understand a patient's needs and what they're feeling. Only then can we begin to more fully assess what barriers might be impeding an optimal health plan and regime, when needed.

Over the course of my career, I've had the opportunity to work with a variety of innovative technologies designed to improve communications and patient engagement – including mobile health technologies such as apps and wearable devices. I believe they hold great promise when it comes to improved engagement and care, but a lot must change before we see useful technologies benefiting all patient populations, and not just the technology-centric consumers more apt to wear a fitness tracker or have a smart phone. No doubt, we'll all benefit greatly from new data sets and interconnected health systems – but while the industry works toward creating and implementing a set of standards and best practices to support these new innovations we must not forget the power of simple, clear, low-tech communications. Sometimes simple is better.

What are some of the top challenges that you and your colleagues face with patient communication?

It is critically important for healthcare professionals to make sure patients understand what is discussed during appointments. For instance, when prescribing medications, doctors must be sure patients can read instructions on medications, and can understand the importance of taking medications as prescribed, including any issues related to the interaction between medications and certain foods.

The Affordable Care Act is providing access to badly needed health care for people who previously had limited access to healthcare. All medical offices need to be prepared to provide culturally appropriate instruction for people with different health care beliefs and upbringing. Acknowledging that a “cold medicine” may be needed for a “hot illness” and that the medications you have prescribed will improve their health can lead to greater compliance and adherence. The process of learning about other cultures and beliefs leads to being a better practitioner and delivering improved care as well.

For our patients with COPD (chronic obstructive pulmonary disease) and diabetes, we have worked with caremessage.org, a group dedicated to empowering patient communities with mobile technology, to provide medical information about care, nutrition, and the emotional impact of chronic disease. Surprisingly, we have seen push back from patients and staff regarding concerns about receiving messages during non-work hours. We have had some parents show remarkable turn-about in knowledge, attitudes and practices, but others who have halted the service after receiving three messages.

We need to continue to innovate and deliver the kinds of tools patients need to play a more active role in their care; to reduce the all too common “disease denial” and improve medication and regimen adherence. To help address some of the resistance, we must also re-cast our messages as “patient decision aids.”



An executive with more than 25 years of experience the health care industry. She brings enormous knowledge and experience both in Massachusetts and nationally measuring patient and family experiences with the health care system and creating innovative and disruptive solutions to engage consumers in their health and health care.

Much has been written about the importance of wellness- and patient-centric healthcare models and approaches, and on the ways in which all key stakeholders must work together to improve patient engagement and the patient experience overall. What are your thoughts on where we are today and the progress we still need to make?

The consumerization of health care is likely to fuel big shifts in the ways patients and families seek and manage their care. Key to authentic patient-centricity is clear and consistent communications; arming physicians and patients with the tools and tips they need to have productive and useful interactions, including making sure that they have the time and space required to do so.

Medicine has changed greatly over the last several decades – your doctor likely utilizes a mobile device or computer during your appointment, and he or she may be able to make a virtual house call or refer you to an app to help you manage your condition. Through all these advancements in technology though we must ensure that every interaction is meaningful, that the patient feels like he/she has a voice, knows what's next and feels like he/she is receiving the best possible healthcare from someone who cares.

We need to make sure patients and families understand what is being discussed, are given ample time to tell their “story” and ask questions, and can follow through on next steps. Technologies can aid in data collection and offer important support tools to patients and families, but must be coupled with great baseline care. As provider and consumer health technologies advance, they have great

potential to improve patient reported data collection, facilitate care coordination and collaboration between physicians and patients and contribute to patients truly feeling that care is centered around their needs and preferences. Moving forward we must come together across the healthcare continuum to deliver on the kind of optimal care and member experience that patients deserve and have come to expect.

Every effort to improve engagement is worthwhile and we can't possibly do too much. I'm optimist about the ways in which so many across health care systems and delivery networks are working toward this common goal.

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About Zaggo, Inc.

Zaggo is national non-profit organization dedicated to providing patients and their family caregivers with the information and tools they need to become empowered, engaged, effective members of their medical teams for the best possible care. With an easy-to-use guide book and organizational tools necessary to keep healthcare information and documents accessible, the ZaggoCare System is the only product to offer the comprehensive advice and tools needed to help patients and caregivers manage illness or injury – and ultimately, receive the best possible care.

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