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shipping and supplies, they are welcome to.

Sue Zalokar: *What does it look like to be a patient on the edge of the health care system?*

Regina Holliday: We are often the folks who are trying to push, right? So any of the patient speakers and activists who do what we do, which is go to conferences and speak, trying to get questions on the floor. We are often asking the hard questions.

A lot of times, at facilities for folks who work there, it is politically dangerous to say certain things – your job could be on the line. Well, invite a patient. We can say it. As soon as something is said, all of a sudden, people can comment on it and they can talk about it. We are the safe crowd that can bring up really hard topics. That has been really powerful to watch that change happening.

S.Z.: *There is a phenomenal article in a recent Harper's Magazine that speaks to just these issues and discusses the participatory medicine movement. For our readers who aren't familiar with this, can you talk about what it is and why it is important?*

R.H.: I've been a part of the Society for Participatory Medicine since 2009. There are a bunch of us who believe that no matter your role in society, you should be a part of your care. And that doctors, providers, nurses, IT professionals, everyone should be together on a team including the patient and the patient or family caregivers.

Many of us who are involved in participatory medicine are also what are called e-patients. We are engaged. We're empowered. We tend to research online. We want to be a member of the health care team. When we talk about things like the medical home model, the idea that there should be a health care team, we think of equal value is the patient and caregiver as team members. Everyone working together will create better care for us all.

S.Z.: *Please share the story of Fred's death and how you came to be a patient's advocate/activist.*

R.H.: I was a regular, normal person who worked in a toy store for 16 years and I taught pre-K art for eight years and I was not involved in health care really. My husband (Fred Holliday) worked at American University between two departments. He was working there in the fall of 2008 when he went to the doctor because he was very fatigued and he was diagnosed with hypertension. We thought that was odd because he had lost so much weight. He was in better shape than he had been in years, in terms of his weight.

In January 2009, he started having really bad rib pain and he went to the ER. They said they saw broken ribs. He had had a bad cough and they said some people explosively cough and break their ribs. We were like, "Really? He's just 38 years old. That seems odd." But apparently it occasionally happens. Then February hit and he wasn't worried about his ribs anymore, his back hurt so bad. We went back to the doctor again and again and she kept giving him pain medication.

By March, he was on four types of pain medication, two of them narcotics, and we had no diagnosis. By March 13 we went to the ER because Fred was hurting so much. They were backed up. They couldn't do any testing. We went the next week to the doctor and I demanded an MRI and afterward, he was told to go to an oncologist. We went to the oncologist and he said we needed to be admitted for tests.

After my husband was there for two days, while he was alone in the room, the doctor came to him and said that he had tumors and growths throughout his abdomen and tumors in his kidneys. He was crying and upset and he called me and asked me to come to the hospital as soon as possible. "I don't know what's going on," he said. I got there in 30 minutes and by the time I got there, the doctor had left town for a medical conference. He'd be gone for four days and he would not respond to e-mails or phone calls.

We had no prognosis, no treatment plan. And later that week when the doctor came back into town, he went to my husband, "So I understand that Mrs. Holliday has been asking questions about this case." And my husband said yes with trepidation. The doctor said that if little Miss Type A personality has questions, she should come to my office hours. So I did.

He never closed the door and he never stopped taking phone calls. And people kept coming in and asking questions and interrupting. I was trying to write everything down because I didn't understand the words he was using and I wanted to research these words later online. I asked him to slow down because I didn't understand his terms. And he told me he didn't like people who did research online. I said, "I'm sorry, but I don't have a background in medicine. My only way to understand you is to research these terms." And he said, "That's right. I'm the one with the medical degree." He made me feel like the size of an ant. My husband was very sick and I was trying to help and understand (what we were dealing with).

I went to get my husband's medical records at the hospital. I learned it would be 73 cents per page and a 21-day wait. I was furious. It would cost hundreds of dollars because we had been (at the hospital) for three weeks. And why make us wait? It's right there in the computer. All you have to do is press print. And they said that's the way it is.

So the next day the doctor came into our room at 9:30 in the morning and said, "We've decided we are sending you home on a PCA (pain treatment) pump." That is a euphemism for not saying the word "hospice." My husband began to cry and I began to cry. I said, "You said you were going to treat us. You said there was going to be a treatment plan." That was when my husband told me to go after them.

I fought for five days for a transfer to another facility for a second opinion. We were finally transferred and sent with an out-of-date and incomplete medical record and transfer summary. It took hours and hours to get Fred back on pain meds and back to being stabilized.

The next day, our new doctors came to me and said, "We need his whole medical record. We just made do for last night. So we're sending you back to the old facility and we're going to ask you to get the whole thing." And I laughed in their faces because I had been trying for four weeks to try to get the medical record and I couldn't get it. And they said, "Don't worry. You're going to be able to get it this time because we're sending you with a courier."

I went back to the original facility and they printed it out in an hour and a half for the new doctors.

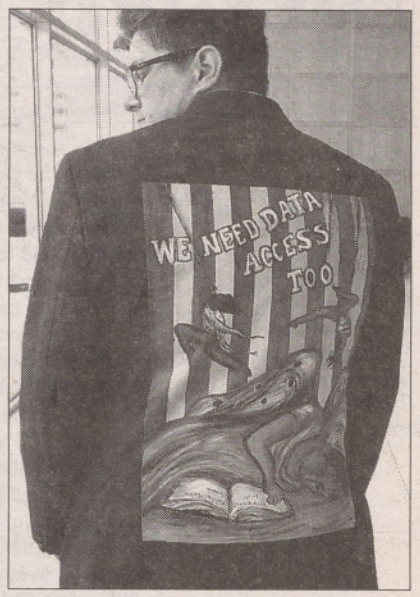
They read it for about three hours and then they handed it to me and I read it. Within three hours I found 13 medical errors. That wasn't the big deal. What was a big deal was that it was full of actionable data that nobody had acted upon in a timely fashion or had not act acted upon at all.

I painted a really big mural on the wall of a local deli in Washington D.C. It was called "Medical Facts Mural" It was basically a nutritional facts label and my husband's medical chart.

S.Z.: *Access to information was life-changing issue for you and your family. What is the history/timeline of Electronic Medical Records and Health Information Technology?*

R.H.: Electronic Medical Record (EMR) technology has been around for a long time, but poorly utilized and implemented. Part of the problem with the rate of adoption of EMR systems was so low. Many facilities up until 'meaningful use' dollars got pumped into the system were still on paper records – 20 years behind at least.

That is really problematic because you're not able to gather data sets. Like what a point-of-sale system does for a store, is amazing. It helps you control inventory, you can run all sorts of reports because computers do things that human beings can't do very well, or at least very quickly. Also, people tend to have bias when we look at things, but computers don't have that problem. They can show you real data. That applies to patients as well. One of the reasons that my husband didn't get diagnosed in a timely fashion is because he was presented as a 38 year-old male who'd recently lost weight and was pretty fit. Well the reason that he had lost all of that weight was because he had cancer eating him up from inside. He was a zebra. Our system doesn't see zebras. You want to see this as a healthy young man; you don't immediately jump to cancer.



"We Need Data Access Too" is the mission of patient advocate Kait B. Roe. She wants to make sure mental health patients also have timely access to data. This jacket, and hundreds similar to it, are part of The Walking Gallery, that uses art to deliver a message of patients' rights to medical venues around the world.

S.Z.: *When I think about my own medical history, it spans the U.S. and many different providers. Is there a way to consolidate my entire history?*

R.H.: Yes. There are companies that do this. They go find your medical record to the best of their ability from all of the different states you've gotten care and different doctors. That is sort of an old school way of doing it.

Now we are going into this concept called Blue Button. The idea is that data holders – your doctor, different insurers – that have data on you, could give it to you for free and you could have a download of that data. And then you could keep that for yourself or you could send it to a third party app that would crunch it for you, make it a readable format.

This is sort of a big deal. Before now, data was considered to have monetary value. It was a commodity. Companies sold that data, they didn't give it away for free. This is a change.

S.Z.: *These days, when I go to see a provider, they aren't using a chart, they are plugging everything into a computer...*

R.H.: It's a closed-data loop. You should ask for your data everywhere you go because most of those systems are legacy-based systems and it's a closed data loop. It doesn't leave the facility.

S.Z.: *And how important is it for others to think about finding or building their own medical history maybe even when they are healthy, before they are injured or become ill?*

R.H.: That is one of the reasons I love 23andMe.com because you get people thinking like that. You can get a lot of information from your own DNA. Ancestery.com is doing this kind of work too and of course there is your family tree that you build out. Those of us who work on the e-patient, participatory medicine kind of movement, the quantified-self movement, visualize a future where your 23andMe-type data, your Ancestery.com data and your electronic health record and your Facebook, all report into the same database. That is a picture of you: your genetic history, your family history, your medical history plus your social history combine to make you.

S.Z.: *You have been a patient's rights advocate since 2009 and have had the chance to experience the health care debate firsthand. What are your thoughts about the Affordable Care Act?*

R.H.: It's a needed step. It's only a step though. We've got a whole staircase to build.

To see a video of the Walking Gallery, visit vimeo.com/80009527

More information about the We Can Do Better conference is available at www.wecandobetter.org

Regina Holliday's mural 73 cents is a feature along Connecticut Avenue in Washington D.C. The mural is 17 feet tall by 70 feet long. "Basically, it is my husband's medical journal written large. Inspiration for the mural came from Jacques-Louis David's "Death of Marat" and Pablo Picasso's "Guernica."