Tough Girl on the Net.
Connected Health: A Patient Narrative

Session 161, March 7, 2018
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Conflict of Interest

M. Maxwell Stroud, MSW, CPHIMSS & Amanda Greene, LA Lupus Lady, have no real or apparent conflicts of interest to report.
Agenda

• Social Media
• Review Learning Objectives
• Using the Patient Narrative as a tool for improvement
• A Patient Story: Tough Girl on the Net
• Q & A and Conversation
Social Media

@MMaxwellStroud
@LALupusLady
Learning Objectives

• Recognize the impacts of connected health gaps on all users of health data, including patients/consumers
• Discuss the differences in health data needs between patients, providers and healthcare organizations
• Summarize the value of including diverse populations when exploring the patient narrative
Patient Narrative Caped Crusaders

SOURCE: Amanda Greene’s Personal Collection
Tough Girl on the Net

Sisters never pack up
We always run back, love
Seven years ago
I said you'd make it so
Sonja was Joanne's friend
Tough girls on the mend
So when I'm feeling small
I toss that cork and call

SOURCE: Amanda Greene's Personal Collection
Connected Health – it a salad bar?

SOURCE: www.iStock.com
The Narrative

Before we get into talking about health records and information, can you tell me a little bit about your healthcare story?
#Goals

You have been living with Chronic Illness for some time now, and have educated yourself extensively about Lupus. What is one of your primary goals for treatment?
Health Tech

How does technology help you meet these goals?

MyChart
Healow
Gmail
Rite-Aid
The Lupus Minder
My Lupus Team
MyMee
I Heart Radio
Twitter
Facebook
Instagram

SOURCE: AppStore Company Logos
The Disconnect

How does technology get in the way of meeting your goals?
Social and Cultural Factors

Basic Information:

• White
• Middle-class background
• College Educated
• Regionally located near many leading academic and research medical institutions
• Married, no children
• History of healthcare activism
Casey Quinlan @MightyCasey · Jan 16

Replies to @MMaxwellStroud @ePatientDave and 2 others

I had to threaten #HIPAA complaint to get scan data released from local hospital group to #rads practice I switched to for follow up scans. Took MONTHS of asking, when I said "HIPAA complaint," magic happened. Crazy.
Kate Sheridan @kate_sheridan1 · Jan 16

Replying to @MMaxwellStroud @ePatientDave and 2 others

One of the most frustrating moments for us was requesting my records from a doctor several times and then receiving a massive PDF file—all of it had to be organized and typed by hand into my PHR on top of managing my illness.
Kirsten: So Very Tired @Kirstie_Schultz · 17 Nov 2017

What do I do on Friday nights? Clearly, the answer is to plot all the labs I've had done as an adult (Nov 2010-now) into Excel.

I mean, duh. #chroniclife
Asked for my medical images
Admin in radiology seemed confused
Now waiting for them to burn me a CD
Had to happen in person #noteasy
I had to cancel one of my new specialists because I couldn’t get my neurosurg records from MGH in time bc I didn’t have access to a fax machine. It wasn’t until I was at my follow up appt in Boston that I walked to their records department and waited an hr for my CD o’re cords.
Records, records, and more #medicalrecords - just getting ready for all of my April #doctor appointments. #RareDisease #chroniclife
Beth Stroud @iестroud · Jan 16

Replying to @MMaxwellStroud

How about when two different doctor's offices use the SAME SYSTEM for their portals, but the only way to transfer health history info is manually?
Replying to @MMaxwellStroud @ePatientDave and 3 others

Sis was in hiking accident & rushed to local hospital. She had to see a specialist at larger facility for immediate follow up. Hospital said weeks to get copies faxed over due to backlog. Sis showed up in person they said up to 3 days to hand over record and to check in each day."
Conversation Topics

• Where do we make assumptions about the patients that we work with and what their needs are?
• What might change if we pivot to a place of deep understanding?
• What can be learned from the patient’s experience?
Conclusions

• Using the patient narrative to explore gaps in health data interoperability can provide critical insight into information that may not be evident from within the healthcare organization.

• Patients have data needs that are different from those of healthcare organizations

• Interoperability should empower patient to have choice in where they receive their healthcare, not limit it.

• Patients should have the ability to easily and quickly share critical health information to new and different health providers.

• Solutions need to consider that not all patients will be as savvy as the person we interviewed today.
Questions

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