



# New windows on patient experience in health care

Blogs, Vlogs, Facebook, and more

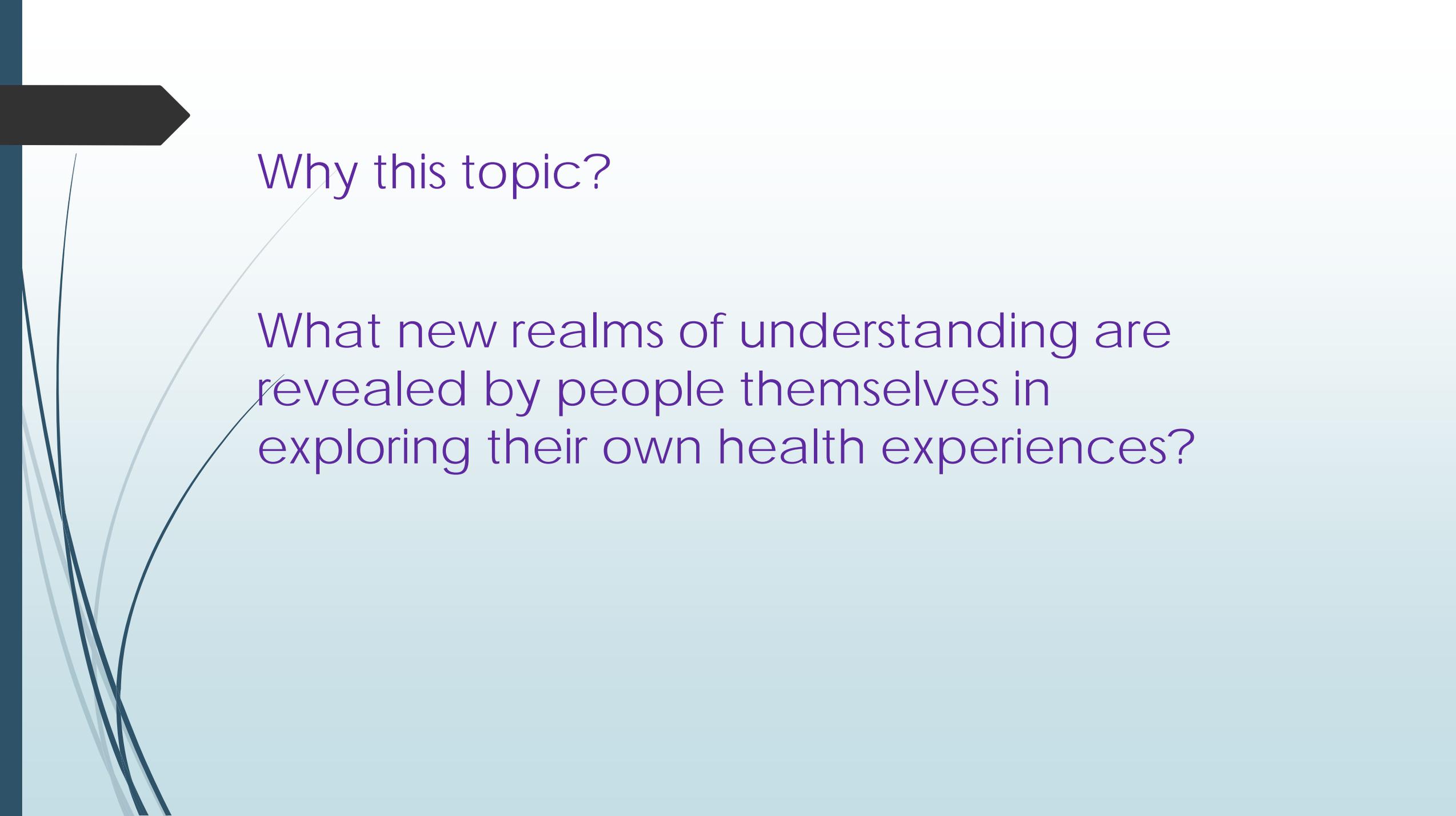


*If I had an hour to solve a problem and  
my life depended on the solution, I would  
spend the first 55 minutes determining the  
proper question to ask*

*– Albert Einstein*

Why this topic?





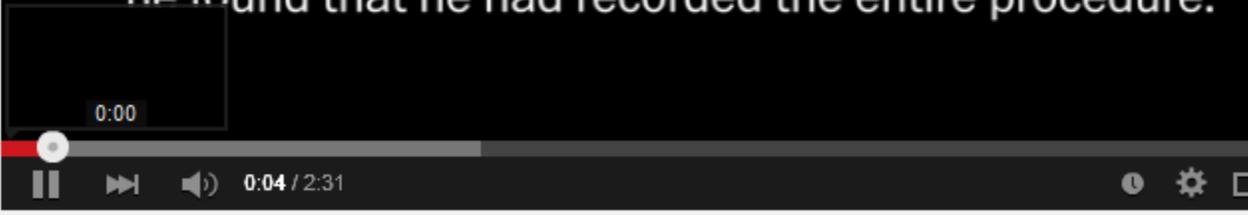
Why this topic?

What new realms of understanding are revealed by people themselves in exploring their own health experiences?

# A PSYCHIATRIST WITH LEWY BODY DEMENTIA (LBD)

A Vienna man receiving a colonoscopy used his phone to record the instructions he would receive from his doctor after the procedure.

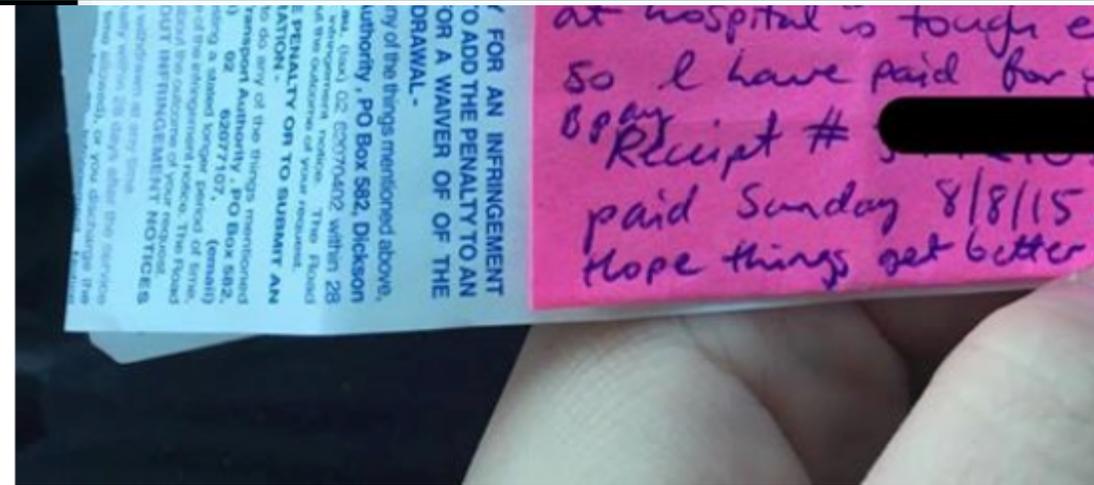
But when he listened on his way home, he found that he had recorded the entire procedure.



Audio: Anesthesiologist trashes sedated patient

#LivingWithTourettes

#ihateyoucancer



### Canberra Mums

Over the past few days I have been in hospital with my 9 week old son. We were discharged today and as I walked to my car I noticed that I had a parking ticket. After those days in hospital, a parking ticket was one more thing that I didn't need. Well to my surprise, when I opened the envelope there was a note from a lovely lady named Laura (attached). I hope that Laura sees this and knows how much I appreciate her support. Thank you so much

August 9  
Alena Bolotov, Jane Prusikova Glikhova, Leanne Craig and 103,270 others like this.

16,158 shares

Emma Kelly Hello, I'm a reporter with The Canberra Times. I just wanted to let the mum who posted this (or even mystery Laura) know that if she was

## Brass and Ivory: Life with MS and

MS and RA patient advocate, Lisa Emrich, shares news and information about living with multiple sclerosis



# What does existing qualitative inquiry on “patient experience of care” look like?

Typical inquiry includes

- ❖ *The Very Specific Question*
- ❖ *The Patient Centered Care Question*
- ❖ *The “Not Really About Health Care” Question*

And uses

- ❖ *Interviews*
- ❖ *Focus Groups*
- ❖ *Surveys with Some Open-Ended Responses*

And it's changing... Recent initiatives stress including patient and family voices broadly in health care, and health care research



# What does this inquiry look like when it uses online/social media data sources?

- ❖ *The Super Specific Question*
- ❖ *Investigating Uses Beneficial to Providers:*
  - ❖ *Distributing patient education materials*
  - ❖ *Marketing*
  - ❖ *Recruiting research subjects*
- ❖ *Quantifying the Qualitative*
- ❖ *Social Media Usage as a Health Risk or Benefit*

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## What COULD this inquiry look like?

- ▶ What if we looked at the CONTENT of what patients collect and make available themselves?



# Patient Perspective – What the Patient Wants to Say

*The entrance to the hospital has an automatic revolving door. It has two sides and allows people in and out through two rather large openings. People come in, people come out. Much like life; our lives move- allowing us to come in to new ventures and out with old ones. No matter if we are entering a new phase in our life, or leaving behind another, we must use the door. The revolving door for a terminal cancer patient, however, is unchanged. I can't pause, I can't get out, and I just keep circling; watching through the glass partition at everyone's lives on the other side that goes in and out.*

[-http://www.thechroniclesofcancer.com/](http://www.thechroniclesofcancer.com/)



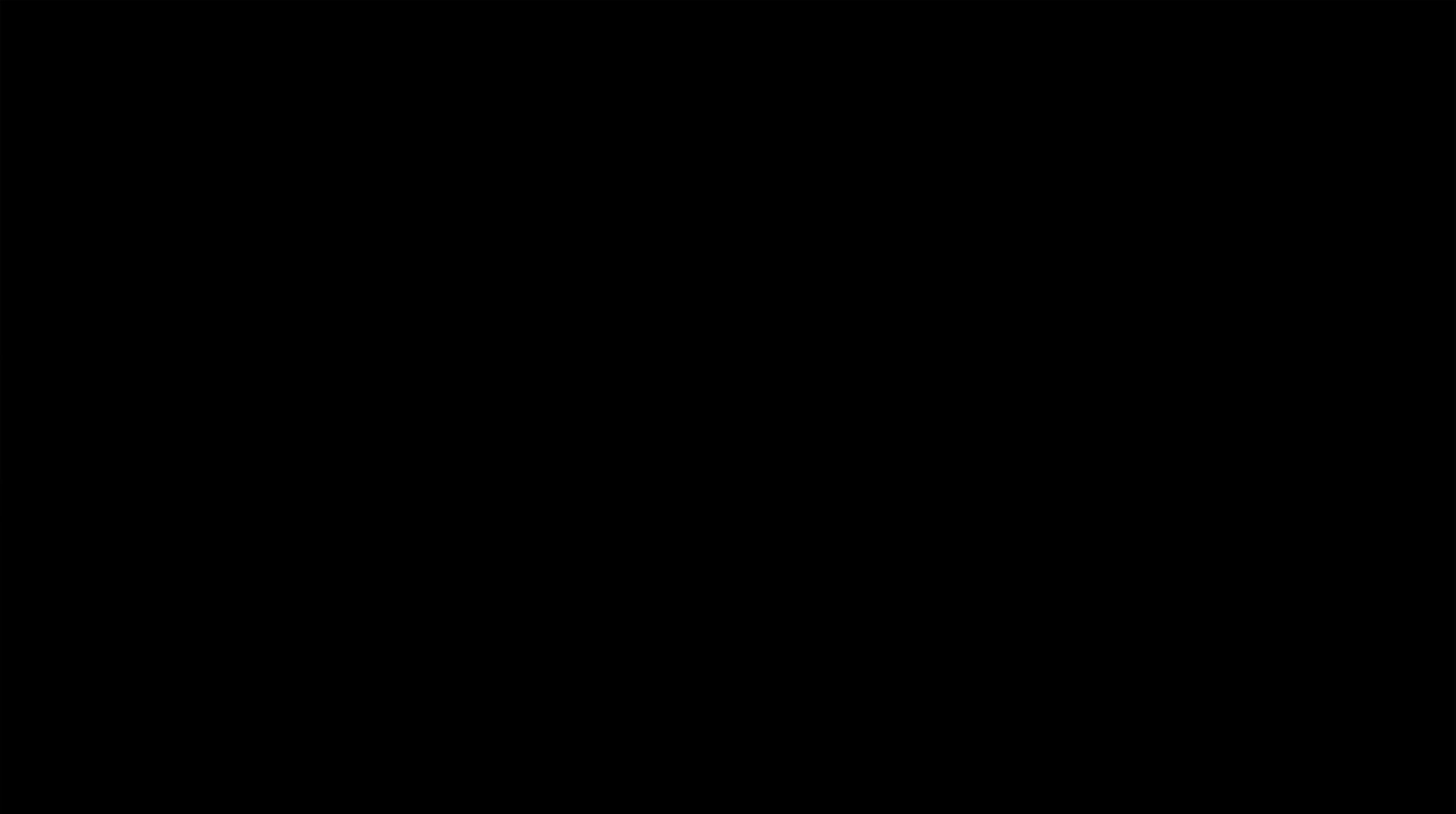
# The potential of social media

- ▶ Find the questions patients and family are already asking or answering, and the data they are using to do it
- ▶ Understand what patients and their family or friends think is important by paying attention to what they focus on and how they communicate it
- ▶ Include patient-generated material in literature reviews along with other grey literature

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## The view is limited, but it is a new view: Source characteristics

- Chronic, life-threatening, or longer term conditions like Lyme disease, cancer, dementia, diabetes, rheumatoid arthritis
- Short and long term hospitalizations like prematurity, stroke, severe injury/accident, planned surgery, heart attack
- Specific types of common experience like the waiting, the not-listening doctor, dealing with insurance, the fantastic nurse



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## Some Early Themes

- *Preserving the home in the context of health care*
- *Connecting to the person, but not always with words*
- *Restoring dignity to the patient*
- *“Getting fixed”*
- *Recording the horror*
- *When words fail: using media to tell the story*
- *What doctor/staff/patient relationship really looks like*
- *Making the resource that was missing*



# *What doctor/staff/patient relationship really looks like*

- ▶ **Videos captured things that patients might not normally talk about or be asked about**
  - ▶ Woman with a chronic illness gives her doctor a rude gesture when his back is turned; other than that, their interaction seems unremarkable
- ▶ **Blogs/Facebook/Twitter capture aspects of the relationship that may be overlooked**
  - ▶ A woman who blogs about creating “smart shirts” for kids with cancer and offering them through cancer centers
  - ▶ #mydoctor, #mydoctorsucks, #ilovemydoctor, #thishospital

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# Making “the resource that was missing”

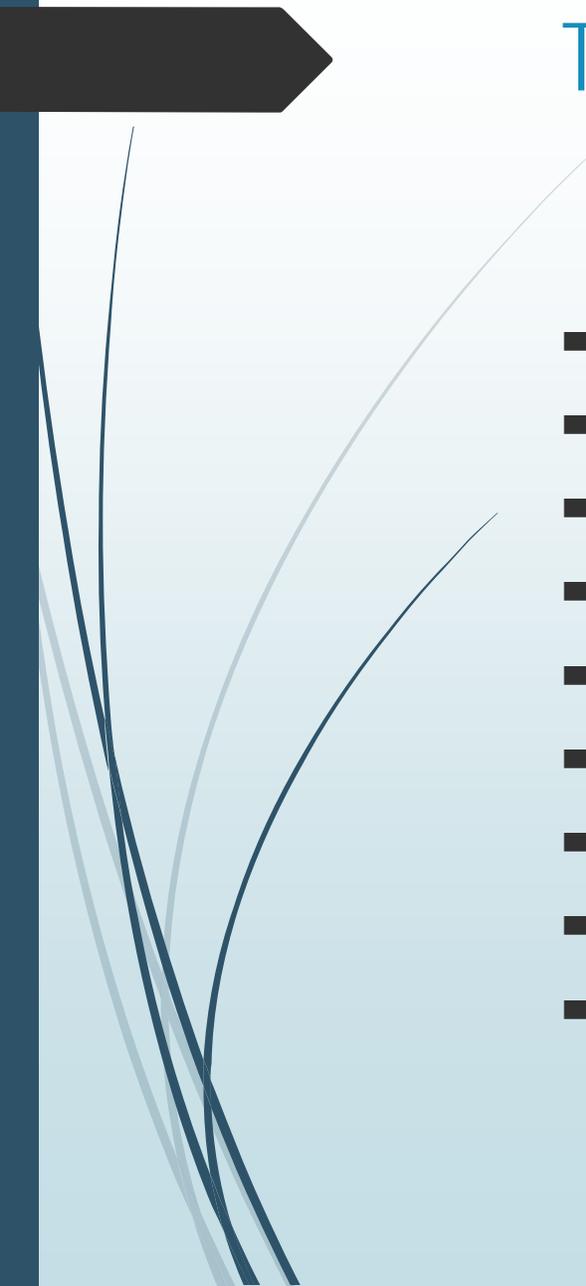
- ▶ *‘I couldn’t find anything good that told me what this surgery would be like’*
- ▶ *‘So people can see what it really looks like to be this sick’*
- ▶ *‘I want to leave this message for doctors out there...there are two patients: the patient and the spouse or caregiver. You need to pay attention to both of them.’*



# Sometimes, the resource is not factual information

- *I overheard a mother weeping ... The update, judging from the amount of crying family members and nurses and doctors outside their glass door, is that there wasn't a lot of time left for their sweet angel. ... I wanted to hug this woman and her family but it wasn't my place. I wanted to tell them they've been so heroic and that they should continue to fight but I would've felt like an intruder. I wanted them to know my wife and I knew exactly what they were feeling but, deep down, I knew it wouldn't have helped dry their tears. Looking back, I wish I said all those things to that child's parents but I was afraid. I was afraid I was looking at my own family's future and quite frankly, that was terrifying. So I said nothing.*

[-http://mom.me/baby/22018-life-picu-through-eyes-father/](http://mom.me/baby/22018-life-picu-through-eyes-father/)

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# Techniques People Use

- ▶ Photo montage
- ▶ Story telling
- ▶ Art and/or graphical overlays
- ▶ Q & A or FAQ formats
- ▶ Sampling of movies and music
- ▶ Presenting and critiquing resources
- ▶ Poetry
- ▶ Summarizing and evaluating research
- ▶ Epistolary





What do patient-created sources of data add to the picture?



*If you want to identify me,  
ask me not where I live,  
or what I like to eat,  
or how I comb my hair,  
but ask me what I am living for,  
in detail,  
ask me what I think is keeping me from living fully  
for the thing I want to live for.*

– Thomas Merton (1915-1968) quoted in a patient Blog



# Roles that only a fellow patient can play?

Why do it? (Decision making process and timing)

You are not alone (Shared experience)

Coping tactics / how I got through it (Try it, it might work for you)

What it feels like (Physical and emotional)

Was it worth it? (Physical, emotional, psychosocial, financial)





# The proper questions?

- ▶ What are patients and family members telling us that we didn't know about [fill in the blank]? How might that help us to improve the quality or safety of care?
- ▶ What parts of health care are best delivered directly by patients to other patients?
- ▶ What parts of training might best be delivered directly by patients to healthcare providers?
- ▶ How do the things patients say in these resources compare to what they say when formally involved in health or in research?



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