

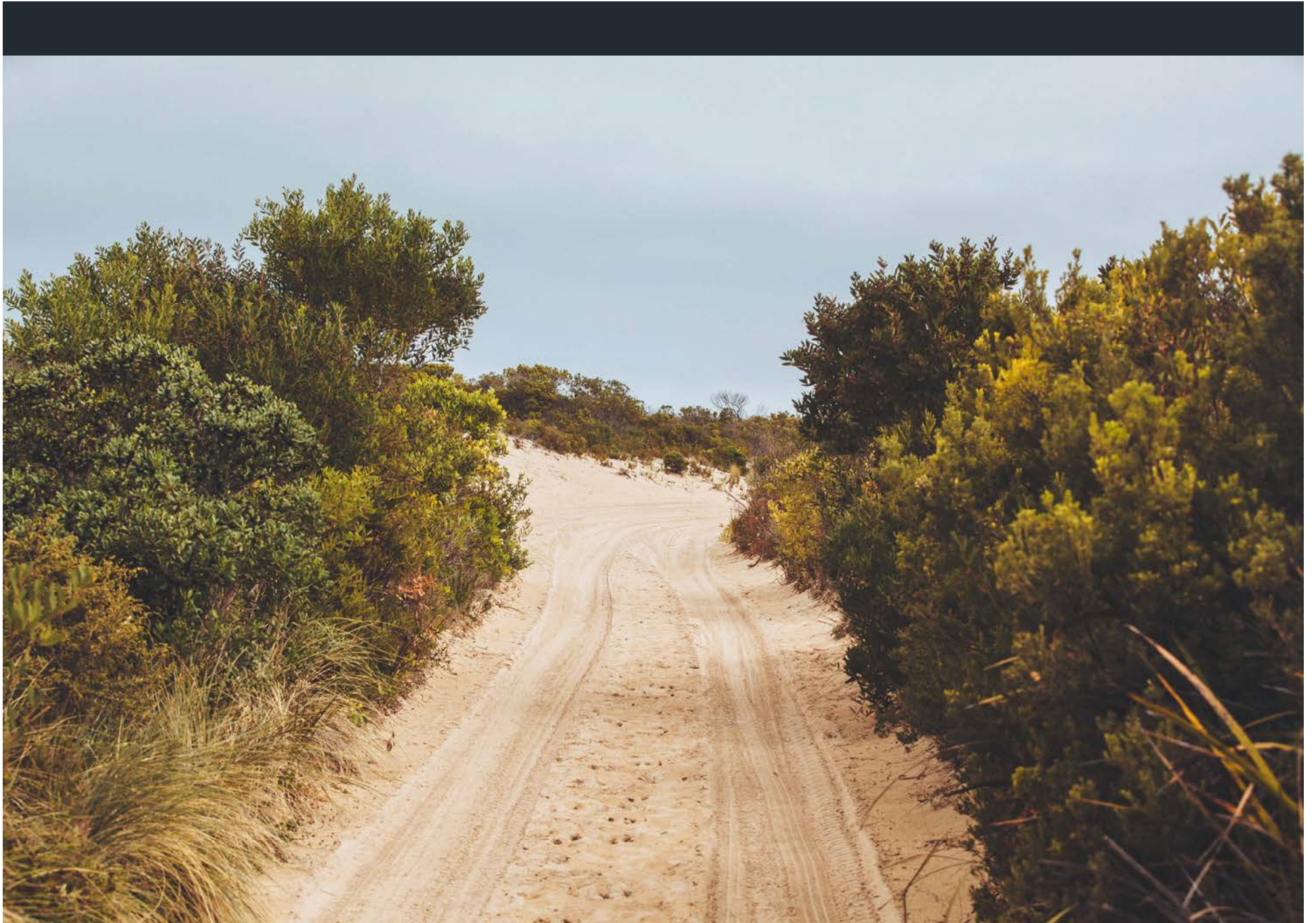


# Patients' View Institute

Using Evidence Based on Experience:  
PVI's "All Patient Centered Data" (APCD)

Pat Mastors & Diane Stollenwerk [www.GoPVI.org](http://www.GoPVI.org)

NYS Health Foundation, August 3, 2016



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# The Healthcare System, as the Industry presents itself:



“We’re here to Help You!”

# The Healthcare System, as Patients experience it...



Hospital – Rehab – Home – Physician – Specialist – Physical Therapist – Insurer – Pharmacist - Labs



... How can I be healthy?

Why don't they listen to me?

Why don't they talk with each other?

What does this information mean?

How much will this cost?

How can I be safe?  
Where can I give feedback / vent / learn / praise / warn others?

How do I find a good doctor?

Why do I need to keep repeating my medical history?

How can I access my medical records?

Why am I getting all these bills? Why are they so high?

Hospital Survey

Which hospital do my doctors work with?

Why wasn't I told about more treatment options?

Why was I sent home so soon? How often do I need to take these pills?

Why won't my insurance cover it?

How am I going to pay for this?

Physician Survey

Why does it take so long to get an appointment?

What is the best hospital?

...grocery shopping – kids' homework – paying bills – caring for elderly – housework – car repairs – work deadlines – attend church – pets – leisure ...

Hospital – Rehab – Home – Physician – Specialist – Physical Therapist – Insurer – Pharmacist - Labs



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How do I find a good doctor?

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Physician Survey

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Why don't they talk with each other?

How can I be safe?

How can I access my medical records?

Why won't my insurance cover it?

What does this information mean?

Where can I give feedback / vent / learn / praise / warn others?

What is the best hospital? Which hospital do my doctors work with?

Why was I sent home so soon? How often do I need to take these pills?

How much will this cost?

Why wasn't I told about more treatment options? Why won't my insurance cover it?

Why am I getting all these bills? Why are they so high? How am I going to pay for this?

...grocery shopping – kids' homework – paying bills – caring for elderly – housework – car repairs – work deadlines – attend church – pets – leisure ...

# What gets measured



**People don't want to be  
surveyed.**

**They want to be heard.**



Here's my story: Who can I tell? Who will listen?





## They're sharing via social media:



**Facebook** "...hospital ratings posted on Facebook appear to correlate with hospital readmission rates and overall quality of care."

Journal of General Internal Medicine, March 2015



**Twitter** "...is a relevant data source to obtain the patient perspective..."

83 % specified type of medical error

52 % expressed frustration

Journal of Patient Safety, January 11, 2016



**Yelp** "...does a better job than the (HCAHPS) survey in rating the quality of hospital stays...went deeper into the patient experience...include the aspects of care *most important to patients and caregivers.*"

Health Affairs, April 2016



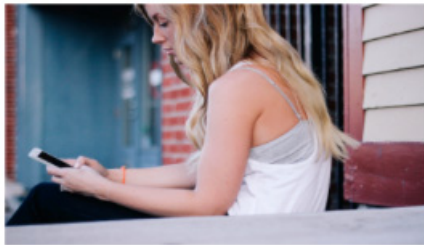
PVI is filling the critical data gap  
between industry surveys

And the real experiences of patients

In their own words...



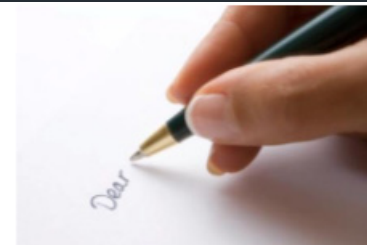
# In their own way.



Text



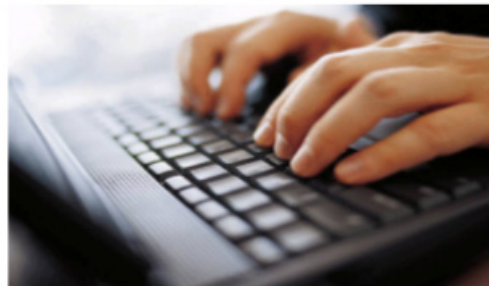
Voice Mail



Snail Mail



To a human being



Email



Photo & video

# ...or Cartoons

## Matters of the Heart

A verse in pictures by Mark Liang

My grandfather died of cancer. Granted, we all knew it was coming. He often tried to make the best of it.

I live within a family of doctors. So we thought we knew the drill.

But being a patient is vitally different than being a doctor.

It's like a mirror... a broken one.

I saw my father and uncles repeat the procedures they've been doing throughout their lives, but on a different side of the wall.

Through the best try his

the worst

and everything in between.

visiting hours discharge

hospice care Hospital first chemo

the fall new nurse TV last meal

was his way to give back, that were people too: people with passions, and happiness to give.

## "Patients have something to give"

I know this because he changed my family for the better when he passed.

He changed me.

I'd like to think that he changed his doctors, his nurses, and all those involved in his care. He would be proud as well that I am sharing this story with the world. He would say that anyone has the power to change lives: doctors and patients, scientists and poets, young and old.



the HEART  
wick.

Fin.



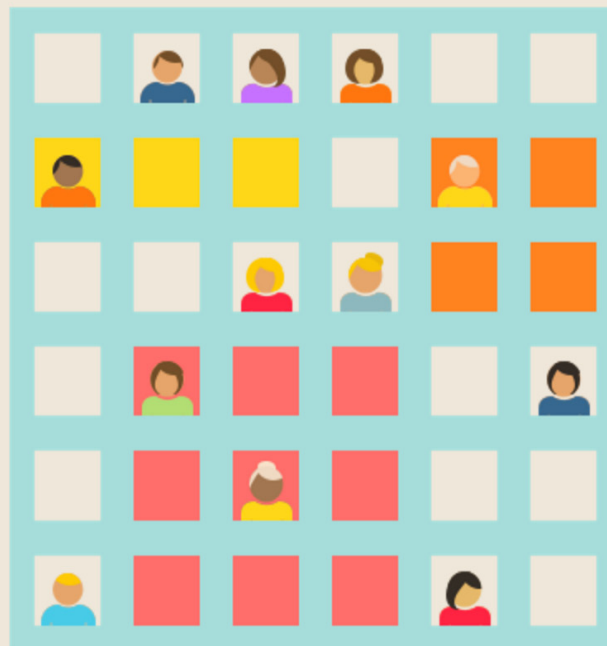
## PVI's "Un-Survey" Approach

Story-gathering process inverts the high cost, derivative "survey" approach, with its prescribed capture format, to distill valuable data from organic content.



# WE COMBINE **STORY** WITH **THE POWER OF DATA**

## STORY + DATA





## Mission

To organize and amplify the patient voice, so patients have more impact on the quality of care we receive and are equal partners in driving improvement in the health care system overall.



## First steps:

Scanning and organizing existing research with patients and families to identify core themes.

**These serve as the basis  
for all PVI activities...**



# THE PATIENT VOICE PRINCIPLES™

What Patients Want and Need Most.



© Patient Voice Institute,  
2016

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- Safety
- Respect
- Information
- Empowerment
- Affordability
- Accountability

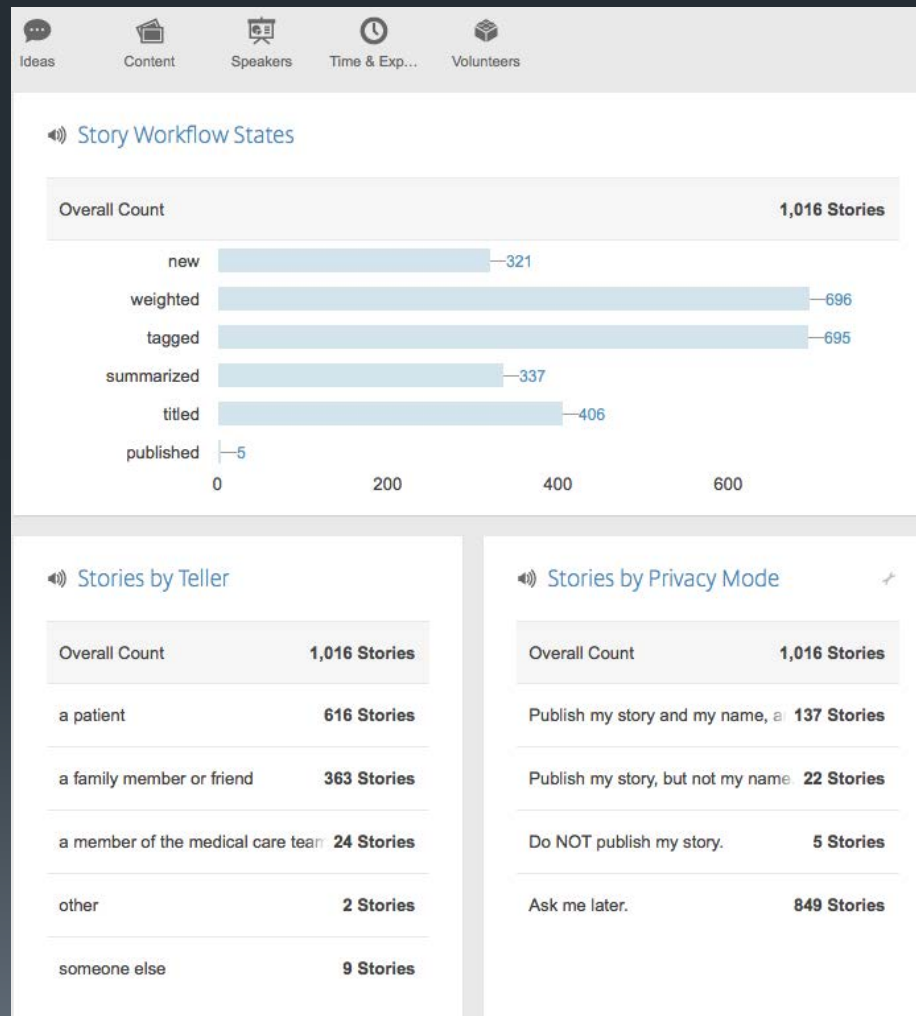


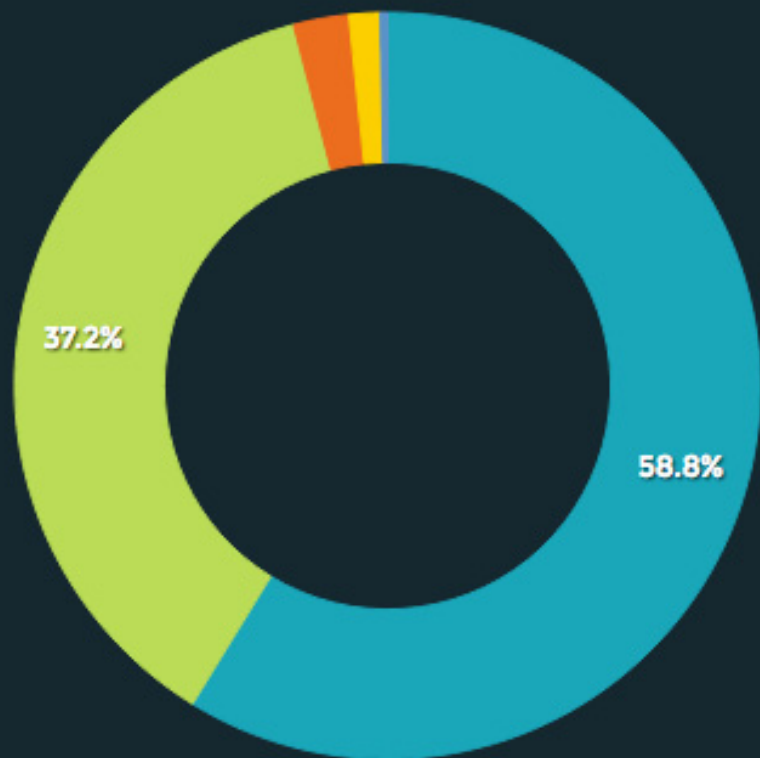
## Stories + Data™ Process

- [www.gopvi.org](http://www.gopvi.org) for story submissions
- Mining existing story databases
- 1,000+ stories collected and tagged (July 2016)
- Standard scale: scored from - 50 to + 50
- Mapped to Patients' View Principles
- Capture insights to refine PV Principles
- Story search to illuminate the data



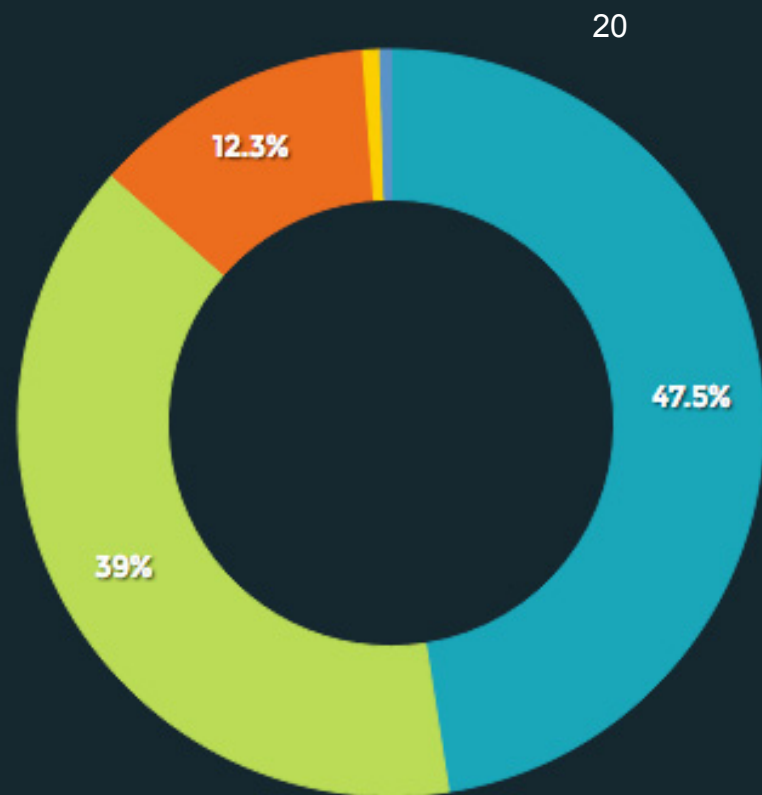
# Insights from PVI HUB: Stories + Data™





I am

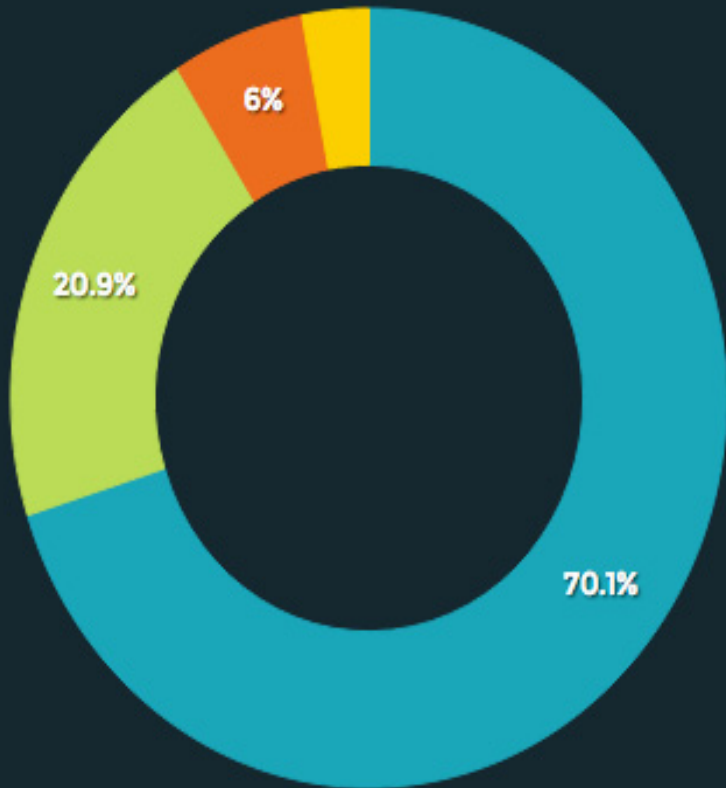
- a patient
- a family member or friend
- a member of the medical care team
- someone else
- other



Story-teller Gender

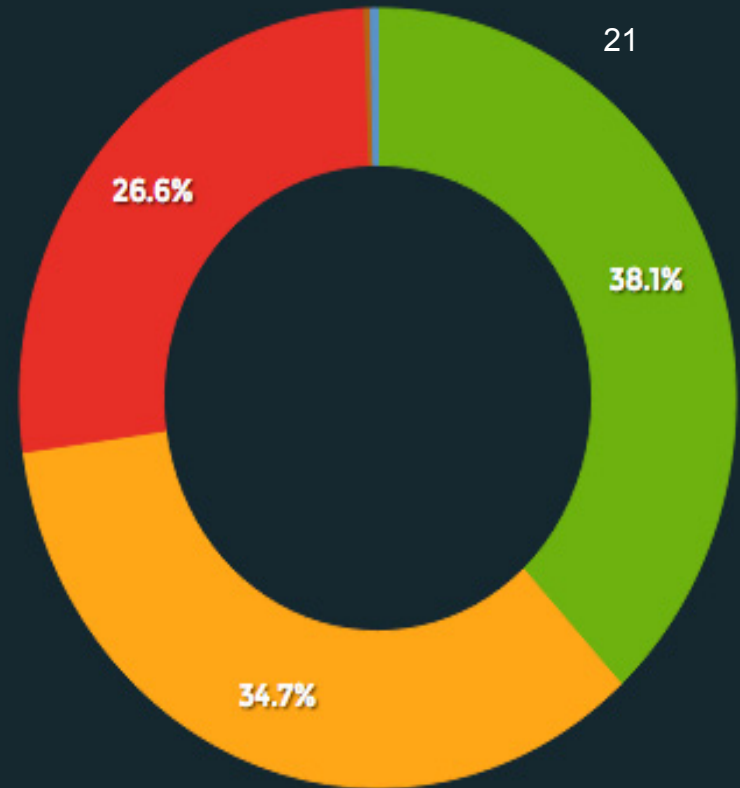
- Unassigned
- female
- male
- #N/A
- 0

20



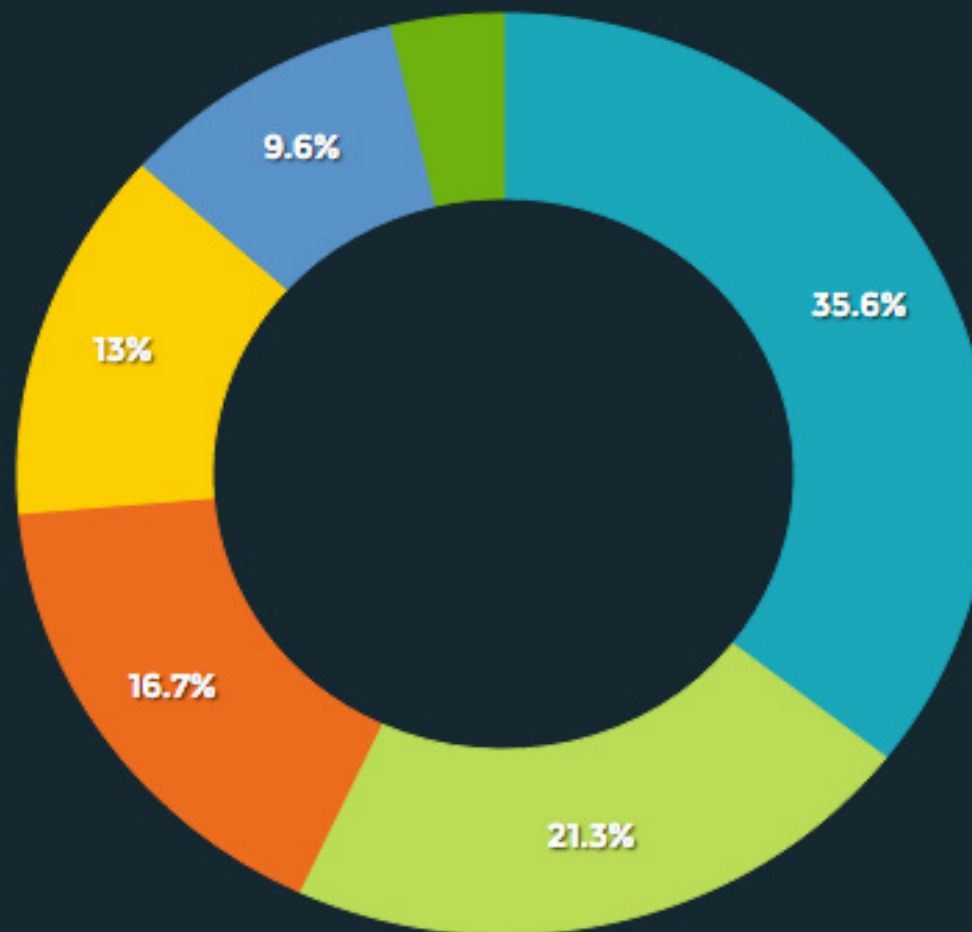
**Privacy**

- Publish my story and my name, and consi...
- Publish my story, but not my name.
- Ask me later.
- Do NOT publish my story.









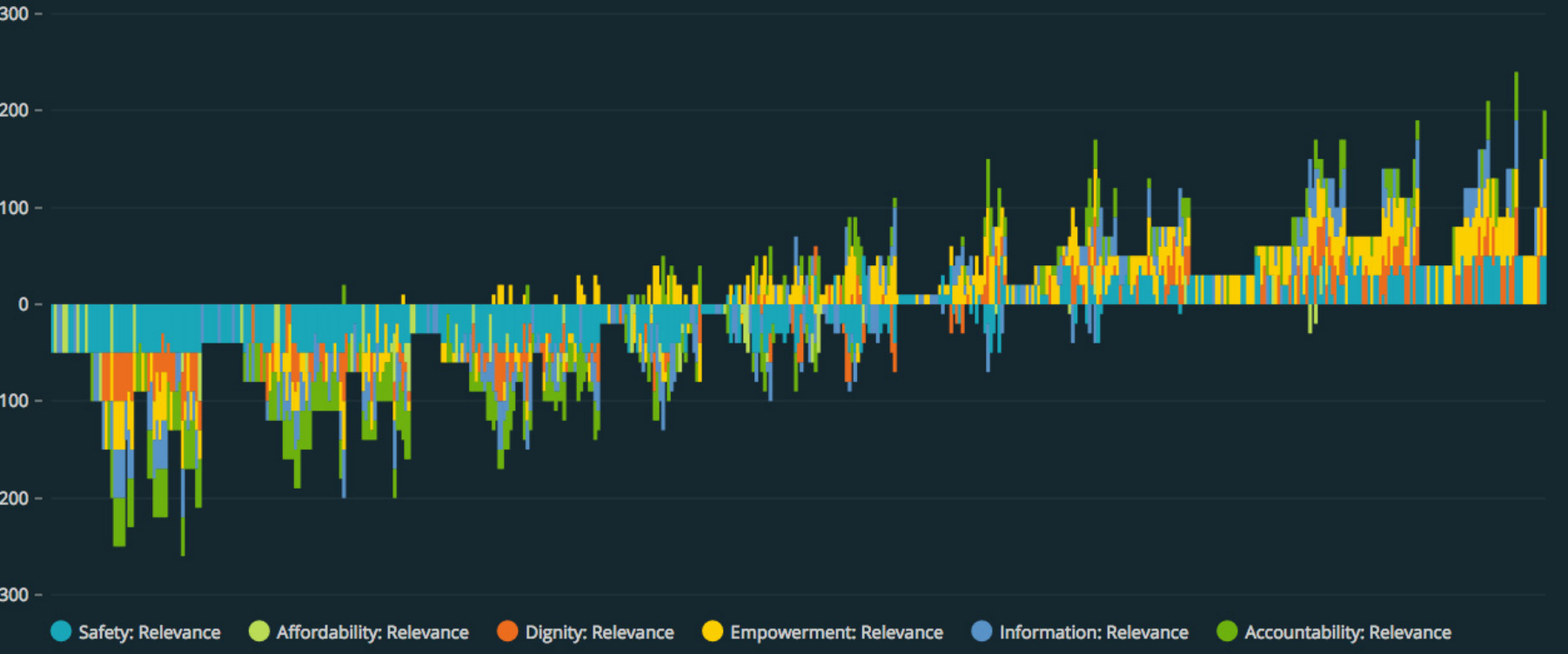
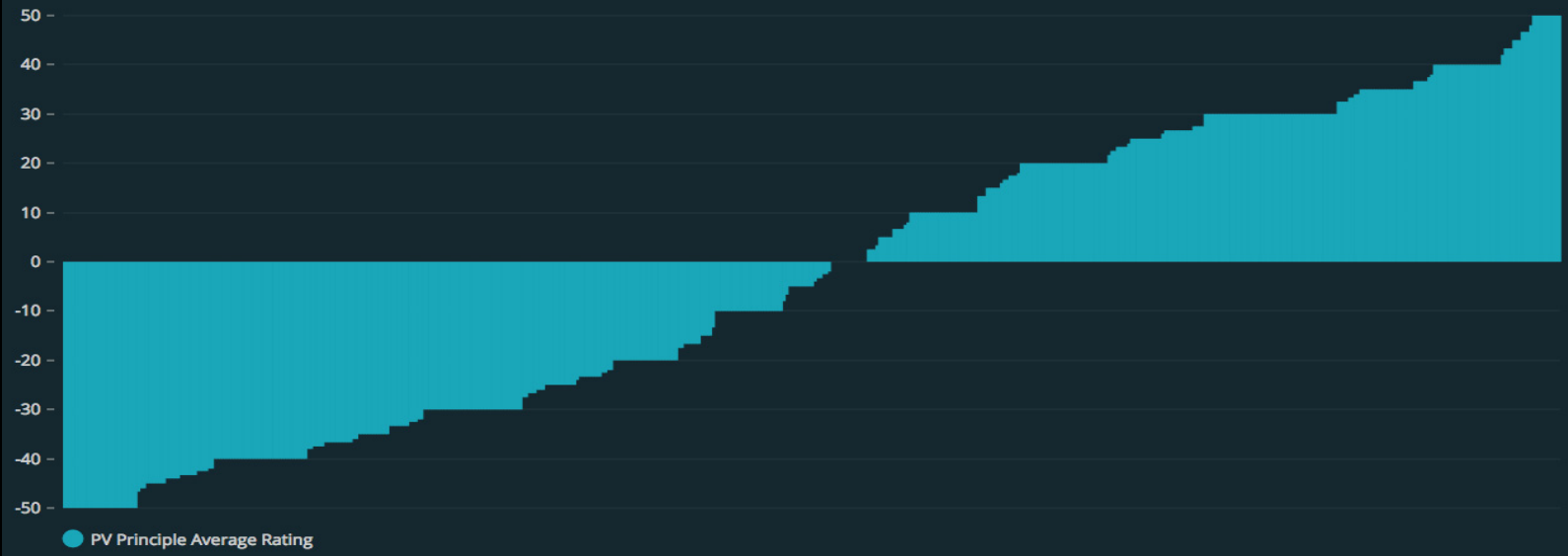
**Patient Gender**

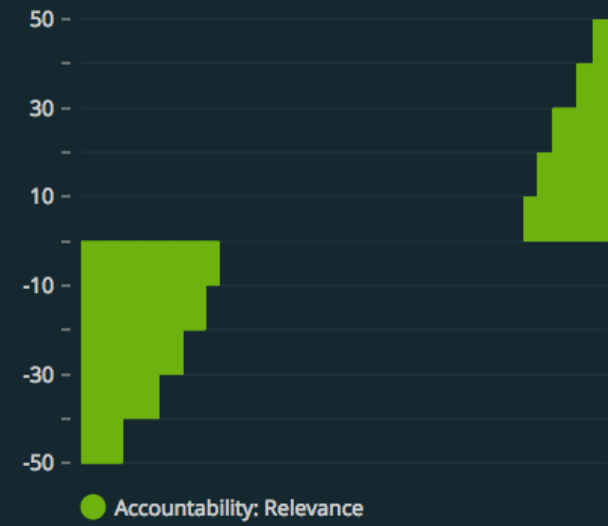
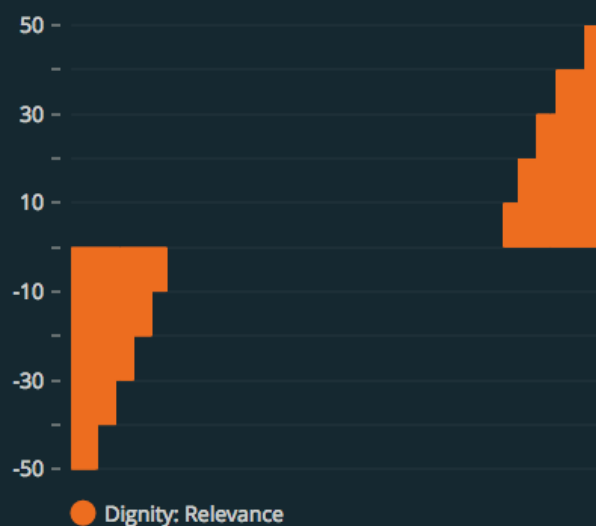
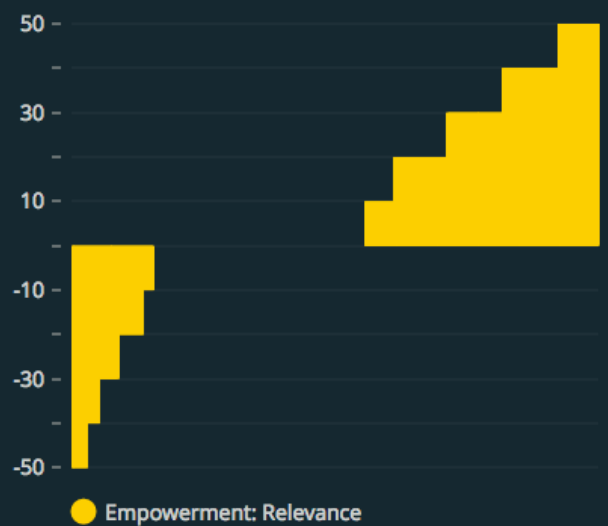
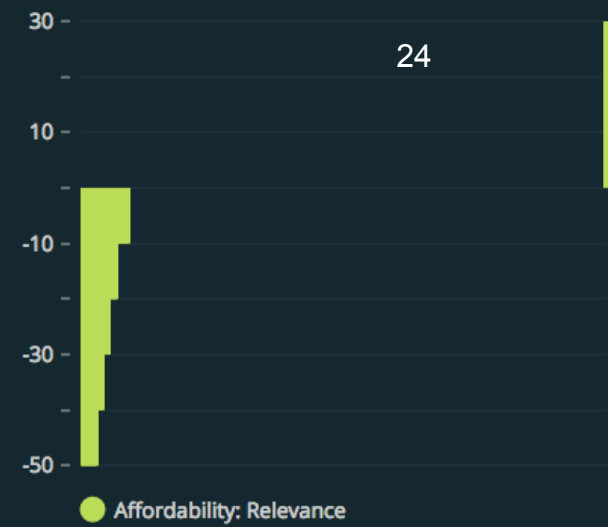
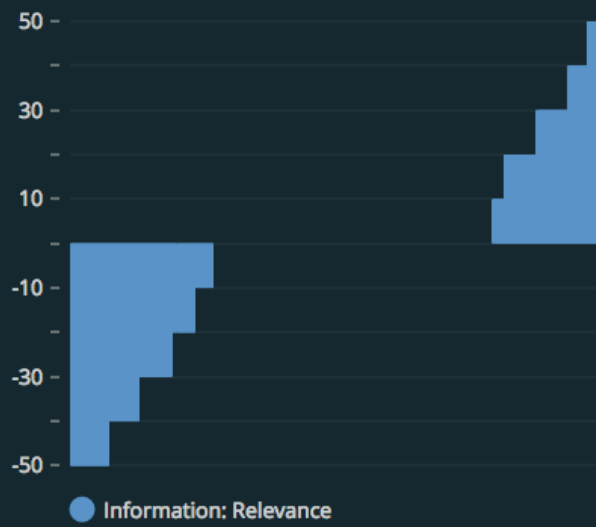
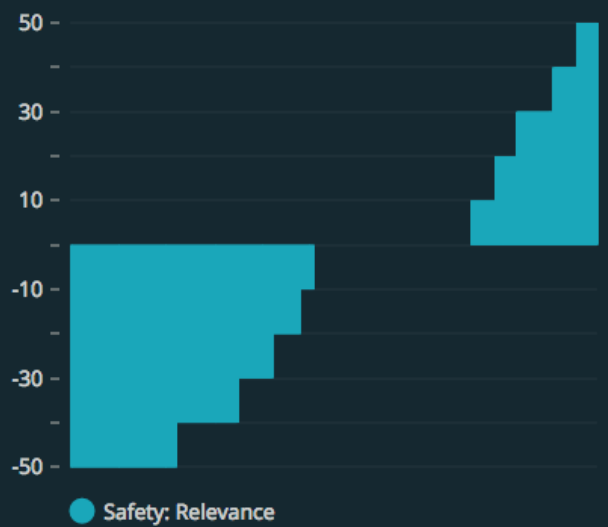
- Unassigned
- female
- male
- 0
- other



### Primary PV Principle(s)

- |                                                                                                 |                                                                                                      |
|-------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------|
|  Safety      |  Empowerment    |
|  Information |  Accountability |
|  Dignity     |  Affordability  |









21 hrs near Mill City, OR

Love that the hospital in Klamath provides patients and their families a way to review progress from far away. Especially since Mom is still at Plum Ridge until her leg is healed enough to go home.

Would love it more if it was in English.

Any help would be appreciated... Is it healing or not? Apparently it hadn't been healing very quickly as of 2 weeks ago, and these are the latest X-ray results. I'm a fairly smart girl, but I only understand like 20% of this.

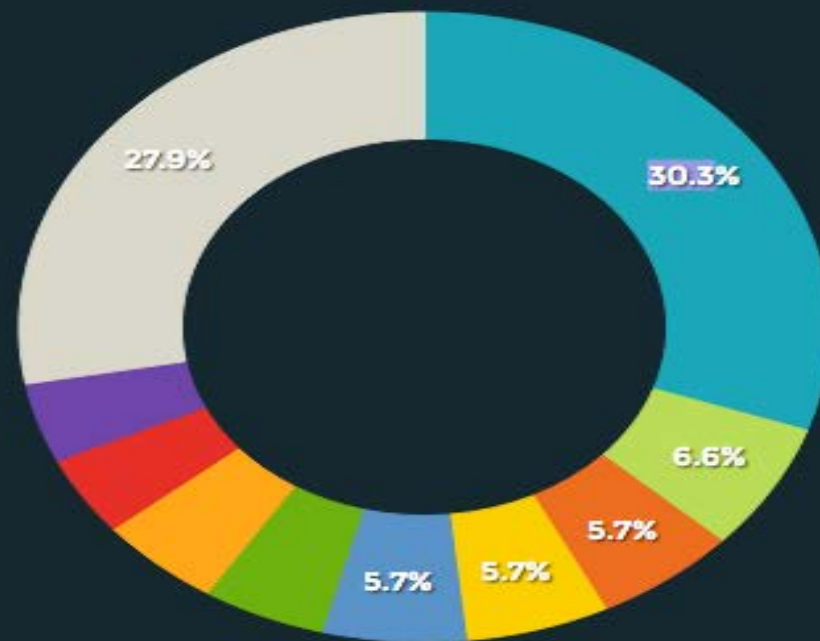


... LATERAL

... Medical Center, CR, XR TIBIA FIBULA

AND LATERAL, 3/10/2016, 19:25. Sky Lakes Medical Center, CR, XR TIBIA FIBULA RIGHT AP AND LATERAL, 3/30/2016, 8:21.

INDICATIONS: Closed extra-articular fracture of distal end of right



### Suggested Solution(s)

- Better communication
- Alternative Therapies
- Better support for family
- Team-Based Care
- treatment plan
- policy change - Policy change
- Proactive testing
- independent patient advocacy
- policy change
- (16 other)



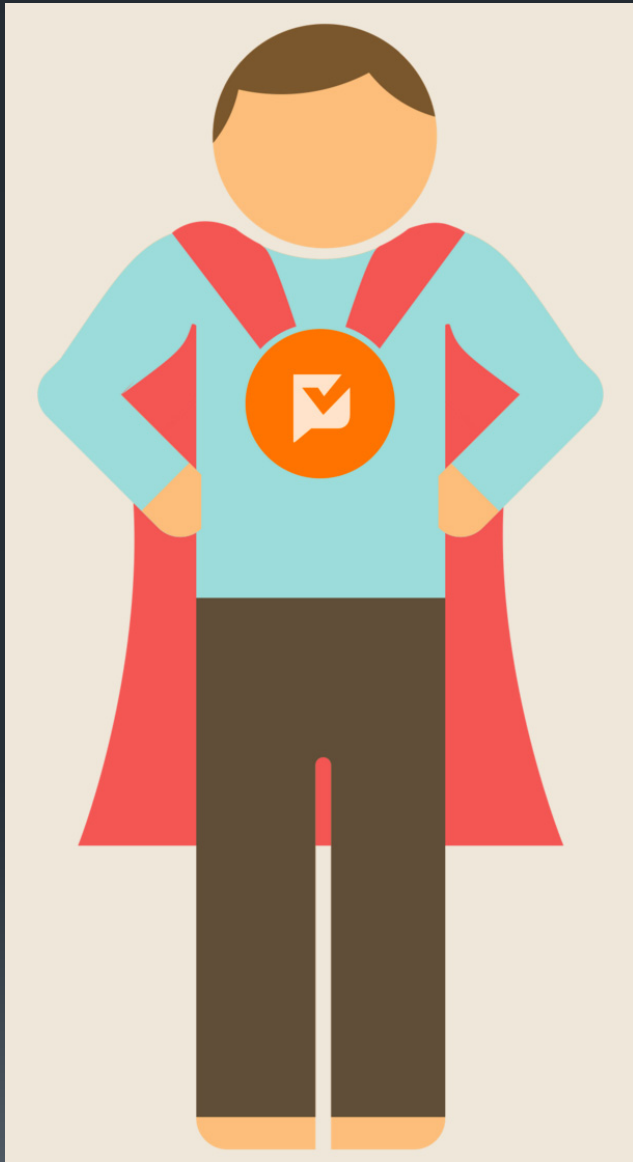
## Insights from Patient Stories

- Experiences are 24/7 and multi-dimensional (*the continuum doesn't start and stop at the facility door*)
  - It's about understandable information
  - It's about timely appointments
  - It's about simplicity (*coordinate the coordinators*)
  - It's about follow up, responsiveness and respect
- No one expects perfection, but let us be involved



# SAFETY

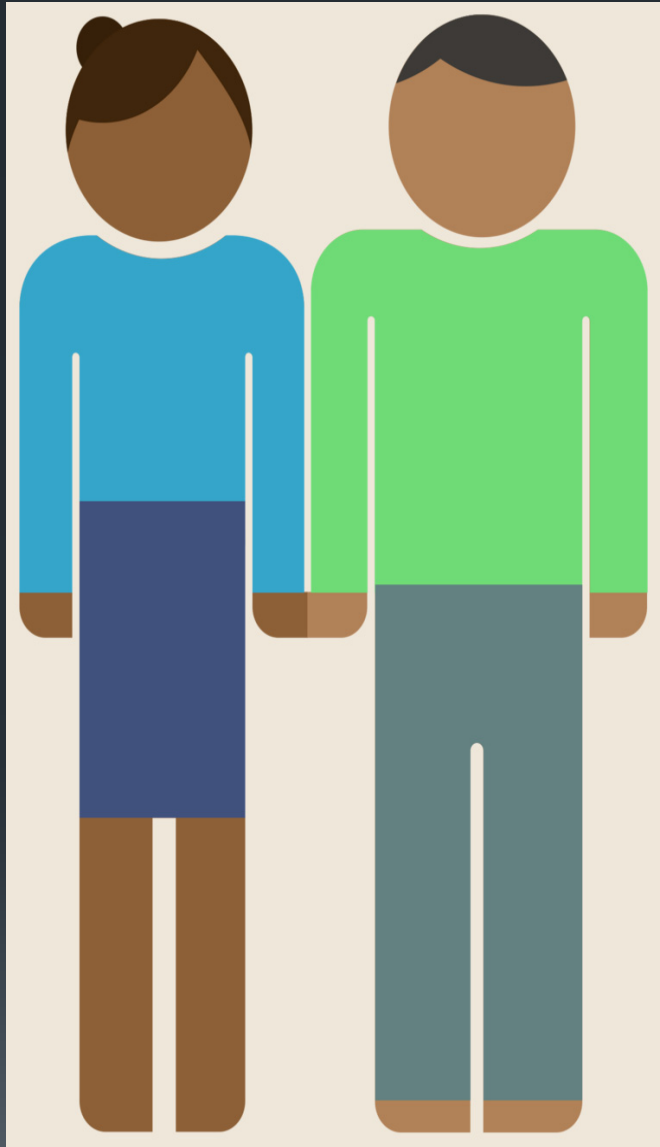
- My safety is the most important thing. I expect:
- Treatment that is up-to-date and consistent with known "best practices", including those that prevent infection and medical mistakes
- Risks, side effects, benefits, cost, and less-invasive alternatives will be discussed with me in advance of treatment
- I'm invited to support my own safety, and shown ways in which I can help
- That my questions are answered and (with some exceptions for emergencies) I'm given time to choose thoughtfully before signing off on a serious medical procedure



# EMPOWERMENT

I feel anxious and vulnerable in the unfamiliar, unpredictable and expensive world of medical care. I expect:

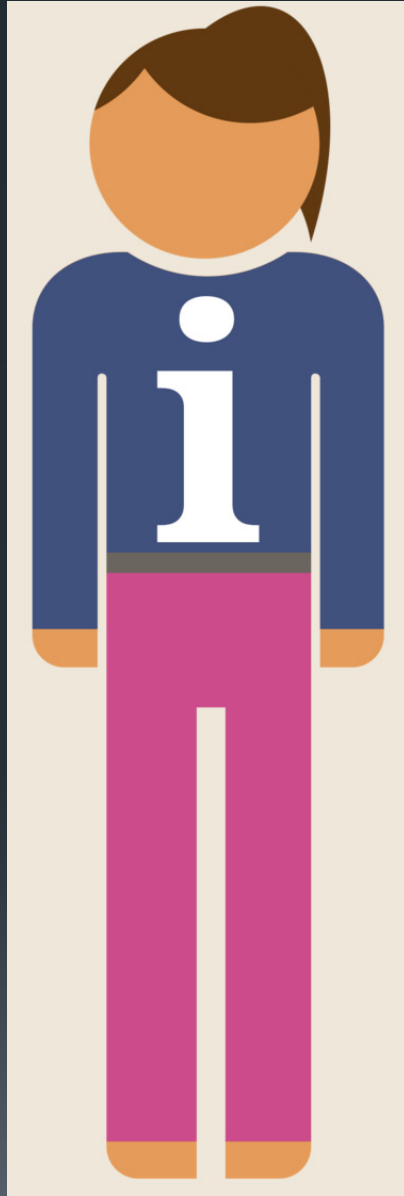
- I am valued as an important partner in my care
- I'm not made to feel lost or unimportant
- Systems and policies are designed to help me navigate with confidence and control over what happens to me
- Data (or its absence) in support of a proposed medication or treatment plan is routinely offered



# RESPECT

I'm treated as a "whole person", rather a collection of body parts or symptoms, with dignity, humanity and respect in all interactions. I expect:

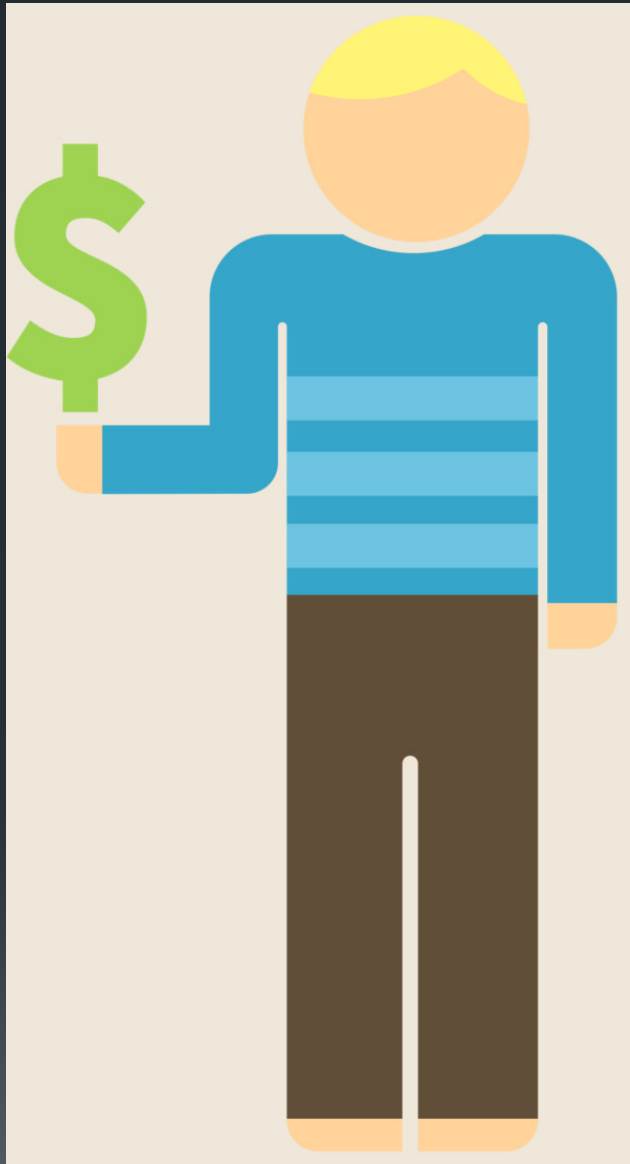
- Treatment without discrimination, and with respect for my culture, values, beliefs and preferences, including the choice of refusing care.
- Care providers listen to me. They knock before entering the room where I'm being treated, introduce themselves, tell me what their job is, look me in the eye, call me by name, explain what they're about to do, and respect that sleep is key to my good health.
- My personal health goals are requested, listened to, recorded and become the framework for my care plan.
- Personal privacy.
- My chosen advocate can stay with me and is made to feel welcome
- If I'm too sick, weak, in pain or otherwise unable to communicate, I'll still get good care and attention.
- An environment of support and respect for staff.



# INFORMATION

I have access to information about me that's important to me. I expect:

- Shared medical records or "open notes" that allow me to look at, review, correct and add to my medical record at any time, including during treatment
- Clear, simple terms are used both when we talk, and in printed materials, including treatment options, health plan benefits, test results, and discharge instructions.
- Access to meaningful reporting on quality, cost and other aspects of the performance of hospitals, health plans, physicians and other care providers, including whether my physician has faced disciplinary action.
- Questions I raise and information I gather independently are viewed as healthy engagement, rather than as a threat to authority.
- I can complain without fear and have my complaints reviewed.
- Patient and consumer representatives are on board helping to shape how programs and plans that affect patients are built, monitored and evaluated.



# AFFORDABILITY

The costs of my treatment plan are addressed. I expect:

- I'll know before service or treatment is provided—whenever possible—what the actual cost will be to me.
- More affordable treatment options, and their relative benefits are offered and explained
- A detailed bill and an explanation of that bill.
- Care is coordinated to reduce duplicate efforts, tests, visits, and wait time.
- Information about resources to help pay for my health care.





# ACCOUNTABILITY

Because medical care can involve many different clinicians, settings and events, I want to be sure things won't "fall through the cracks." I expect:

- A "team-based" approach to care that puts everyone on the same page
- One designated point person who works in partnership with me and my advocate(s), and takes responsibility for my overall care plan
- In the hospital or other medical facility, I and/or my advocate are included in conversations where my care is handed over during a shift change
- Measures, ratings and reports that show me how clinicians and hospitals are held accountable, as well as how other patients felt about the care they received.
- When something bad unexpectedly happens, the information is disclosed to me in a timely way, and where appropriate, efforts are made to make me whole.
- The lessons learned from my case—including from any mistakes in my care—are used to make things better for the next patient.



## How PVI Applies Stories + Data™

- Continually refining the Patients' View Principles
- Developing materials for use in training for patients, to deepen expertise and engagement at all levels
- Materials to inform health care organizations
- Research and policy discussions to inform
  - Patient-centered care
  - Patient and family engagement



# A Few Examples of Impact...

- Giving a Voice to Patients
  - Patients' View Impact Awards at Leapfrog Meeting in Washington DC
  - Media coverage, including USA Today
  - Presentations at conferences and events (PVI Speakers Bureau)
- Informing Policy
  - Measure Concepts for Patient and Family Engagement
  - Principles for Use in Patient-Centered Measurement
- Informing Research
  - AIR: Center for Patient and Consumer Engagement
  - Academy Health Project to Expand Outreach & Refine Methodology



# Patients' View Institute

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