

# *Measure for Measure:*

A patient and caregiver perspective in aligning quality measures

Testimony by Regina Holliday, Patient Artist Advocate

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS QUALITY SUBCOMMITTEE HEARING  
on Measures that Matter to Consumers on February 28, 2012



*All italicized quotes are attributed to William Shakespeare in **Measure for Measure**.*



*“The law hath not been dead, though it hath slept.”*

Daily 25,000 patients are surveyed about their hospital experience;  
each day more than 7,500 patients complete the HCAHPS survey



As of 2013, The Total Performance Score for Hospital VBP (Value Based Purchasing) will have two components

Clinical Process Domain,  
accounts for 70% of the Total Performance Score;

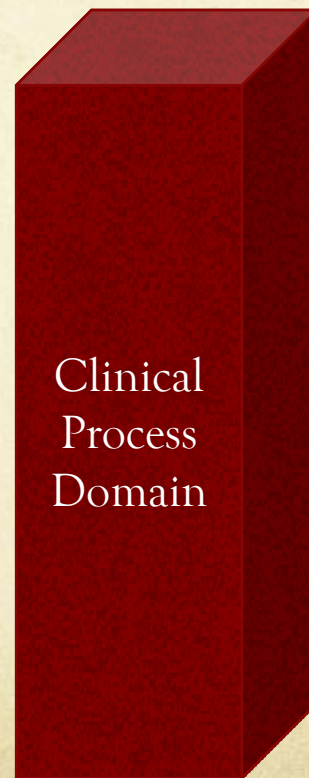
Patient Experience Domain,  
accounts for 30% of the Total Performance Score.

Let's look at how that aligns.

# a•lign•ment (-lnmnt)n.

1. Arrangement or position in a straight line or in parallel lines.
- 2.a. The process of adjusting parts so that they are in proper relative position: A set of gears needs periodic alignment.
- b. The condition of having parts so adjusted: Binocular lenses that are out of alignment will yield a double image.

100 \_  
90 \_  
80 \_  
70 \_  
60 \_  
50 \_  
40 \_  
30 \_  
20 \_  
10 \_  
0 \_





The HCAHPS  
Scores of two  
local hospitals.



If this Patient Hospital Experience  
was depicted using a child's report card,  
we would see

C's, D's,  
*and* F's.

Patients who reported that their nurses "Always" communicated well.	67%	67%
Patients who reported that their doctors "Always" communicated well.	74%	76%
Patients who reported that they "Always" received help as soon as they wanted.	55%	51%
Patients who reported that their pain was "Always" well controlled.	62%	67%
Patients who reported that staff "Always" explained about medicines before giving it to them.	51%	53%
Patients who reported that their room and bathroom were "Always" clean.	61%	68%
Patients who reported that the area around their room was "Always" quiet at night.	56%	47%
Patients at each hospital who reported that YES, they were given information about what to do during their recovery at home.	76%	74%
Patients who gave their hospital a rating of 9 or 10 on a scale from 0 (lowest) to 10 (highest).	60%	62%
Patients who reported YES, they would definitely recommend the hospital.	66%	73%

Outpatients having surgery who got an antibiotic at the right time - within one hour before surgery (higher numbers are better)	Not Available <sup>5</sup>	87%
Outpatients having surgery who got the right kind of antibiotic (higher numbers are better)	Not Available <sup>5</sup>	86%
Surgery patients who were taking heart drugs called beta blockers before coming to the hospital, who were kept on the beta blockers during the period just before and after their surgery	99% <sup>2</sup>	96% <sup>2</sup>
Surgery patients who were given an antibiotic at the right time (within one hour before surgery) to help prevent infection	98% <sup>2</sup>	95% <sup>2</sup>
Surgery patients who were given the right kind of antibiotic to help prevent infection	99% <sup>2</sup>	95% <sup>2</sup>
Surgery patients whose preventive antibiotics were stopped at the right time (within 24 hours after surgery)	98% <sup>2</sup>	98% <sup>2</sup>
Heart surgery patients whose blood sugar (blood glucose) is kept under good control in the days right after surgery	Not Available <sup>2</sup>	Not Available <sup>2</sup>
Surgery patients needing hair removed from the surgical area before surgery, who had hair removed using a safer method (electric clippers or hair removal cream - not a razor)	100% <sup>2</sup>	100% <sup>2</sup>
Surgery patients whose urinary catheters were removed on the first or second day after surgery	99% <sup>2</sup>	95% <sup>2</sup>
 Patients having surgery who were actively warmed in the operating room or whose body temperature was near normal by the end of surgery	100% <sup>2</sup>	99% <sup>2</sup>
Surgery patients whose doctors ordered treatments to prevent blood clots after certain types of surgeries	96% <sup>2</sup>	98% <sup>2</sup>
Patients who got treatment at the right time (within 24 hours before or after their surgery) to help prevent blood clots after certain types of surgery	96% <sup>2</sup>	98% <sup>2</sup>

This is a comparison of the same hospitals, but now presented from the clinical view using process of care measures.

In this Report Card, we see the scores vary from

B<sup>+</sup> to A<sup>+</sup>





Now let's analyze the ramifications of this divided view.



**The Patient View:**

"Patient perception of care" is a whole lot more than making sure nurses and doctors are friendly and smiling. It's about saving lives and delivering safe healthcare. It's about quality in a very real, concrete way.

-The HCAHPS Handbook, Studer Group

**The Clinical View:**

"Diseases are the "real" things- the things that count. Symptoms are a second-best access to the disease entity, the best being "direct" views, such as X-rays, tissue examinations, electrocardiograms and so on. From the same perspective sick persons, as persons, are a agglomeration of "soft data" - feelings, emotions, values and beliefs- in these terms, not as real as their diseases."

-The Nature of Suffering, Eric J. Cassel

## What measures matter to patients?

- Patients must be able to access their entire record in a timely fashion and populate it with qualitative as well as clinical data.
- Patients should be an active part of the data capture process from triage to discharge and beyond. They should have patient equivalencies to CPOE and CDS.
- Patients who are part of rare disease populations should have the right to share their data if they so desire, even if it is not possible to completely de-identify.
- Patients with impaired mental health should be able to access and comment in the medical record.
- Patients with disabilities should have appropriate accommodations to access the medical record and provide feedback.
- Parents should be asked to actively engage with and through the electronic health record while experiencing the pregnancy journey and children should play an active part in patient education.
- Errors in care should be fully revealed and greater learning embraced through admitting mistakes and rectifying the care process so such events should not occur again.
- Health literacy should impart a clear understanding of important hygiene practices.
- The reason's for patient non-compliance should be addressed on a case by case basis.
- A statistically significant autopsy rate must be reinstated.
- Measures must be re-evaluated as technology changes and we must guard against the misapplication of the laws' intent.
- In the pursuit of data aggregation, the individual voice must not be silenced.
- Patients must be included in the design & implementation of measures and have a voice within committees such as this one.





We must share in the creation of our data sets and compare like to like.



*“What’s mine is yours, and what is yours is mine.”*



## *“Condemn the fault, and not the actor of it.”*

Currently patients have limited access to their medical record. In some cases, no access is available until discharge. In a best case scenario, the access consists of labs, imaging reports, discharge summaries and medical administration records.

Rarely does a patient have access to the doctor's progress notes, nurse's progress notes or medical administration reports.

Very few patients can add to the medical record in real-time, adding either clinical patient reported data or the “soft” subjective data of personal experience.

The HCAHPS surveys are sent to a sample of patients 48 hours to six weeks post discharge.

Patients are expected to submit their responses *based on their memory.*





The clinical data set is provided through Medicare claims data and additional data submissions from the hospital EHR.

This data was created in real time using Clinical Decision Support or Computerized Physician Order Entry.

Providers are **not** expected to remember events that unfolded up to six weeks before and report on them.





## *“The demi-god, Authority”*



## The Patient Portal and Clinical Decision Support for Patients

In order to create patient measures that have equal weight compared to clinical measures, patients/caregivers must have access to the tools of data creation and capture.

Only then can we attain an equal footing.

Patients must be part of the active data creation process from triage, through the entire episode of care culminating in a personal qualitative discharge summary.

*“The miserable have no other medicine, but only hope.”*



Many patients are part of online patient communities and openly share data.

Some patients with rare diseases want to share data. Measures should include input from rare disease patients whenever possible.

Although concerns exist that a small data pool can lead to the identification of an individual patient, the patient should be asked if they would like to be included in such data sets rather than being subject to a default decision of exclusion.





We must also consider the views of those who have little access to information due to mental health status.

Their need for data access is great and so is their need for appropriate survey questions.

Too many patients cry for solace with no recourse.

Pain can be treated in many ways but the journey starts with recognition of the individual voice.



Patients with disabilities may need accommodations to fully participate in qualitative and quantitative data capture.

No one should feel left out of this process as every voice is important.



*“Haste still pays haste, and leisure answers leisure;  
like doth quit like, and Measure still for Measure.”*



Measures should encourage data capture at the beginning of the patient journey.

At the birth of a child many parents are fully engaged in the health care process, they should be included by survey questions that apply to their unique experience. Further, this window of time can create a parent who is empowered in their health care choices as well as teaching the young to be empowered as well.

At the beginning of a child's health care journey they are open to fully embracing ownership of their personal health. We must reach out such young ones and include them as well. If a child can write they can take part in building their patient story.

*“They say, best men are moulded out of faults,  
And, for the most,  
become much more the better for being a little bad.”*



Patients want to partner with their providers in the creation of the medical record, such patient access allows errors of miscommunication to be corrected in a timely fashion.

We all make mistakes within an episode of care, but it is a fool who refuses to learn from their mistakes.

Often the mistakes we make sear a cognitive path within our mind and we learn life-long lessons if we address our failings.



Patients who reported that their room and bathroom were “Always” clean...



How do we define clean? How does that differ from disinfected?

Should we be asking if the staff “Always” washed their hands?

Has the patient been informed about the dangers of hospital acquired infections?



*“Some rise by sin, and some by virtue fall.”*



“Patients are not compliant” is the refrain echoed at medical practices and conferences.

With one stroke of the brush,  
whole populations are painted with scarlet shame.

Measures should reflect both populations and personal choice. If patients are non-compliant, we must discern the barriers that the patient faces in their journey to better health or their journey to a peaceful death.



Measurement cannot exist unless access is open and transparent, and this transparency must continue unto the end. In order to provide necessary data for evidence based medicine we must reinstate a statistically significant autopsy rate.

In the United States; hospital autopsy rates of 60% in the 1950s fell to 12% in the early 1990s and less than 5% in nonteaching hospitals.\*

Private autopsy services begin at \$2,000.00 and are far out of reach of many consumers.

In addition, studies find that there is disagreement between pre and post-mortem diagnoses in almost 30% of cases.



*“Truth is truth to the end of reckoning.”*



*“We must not make a scarecrow of the law, setting it up to fear the birds of prey,  
And let it keep one shape, till custom make it their perch and not their terror.”*



We must consistently re-evaluate the measures we are using to determine they are still assuring the quality of care in the patient population.

For all too often the law is twisted and bent to serve a new purpose.

Legislation designed to allow for openness and access can become the legislation of restraint.

It is our duty as both patients and providers to support the original intent of quality measures while constantly updating the means.



*“O! it is excellent to have a giant's strength, but it is tyrannous to use it like a giant.”*



As our data base of measurement grows we will be able to apply the principles of evidence based medicine to large patient populations ensuring more appropriate care.

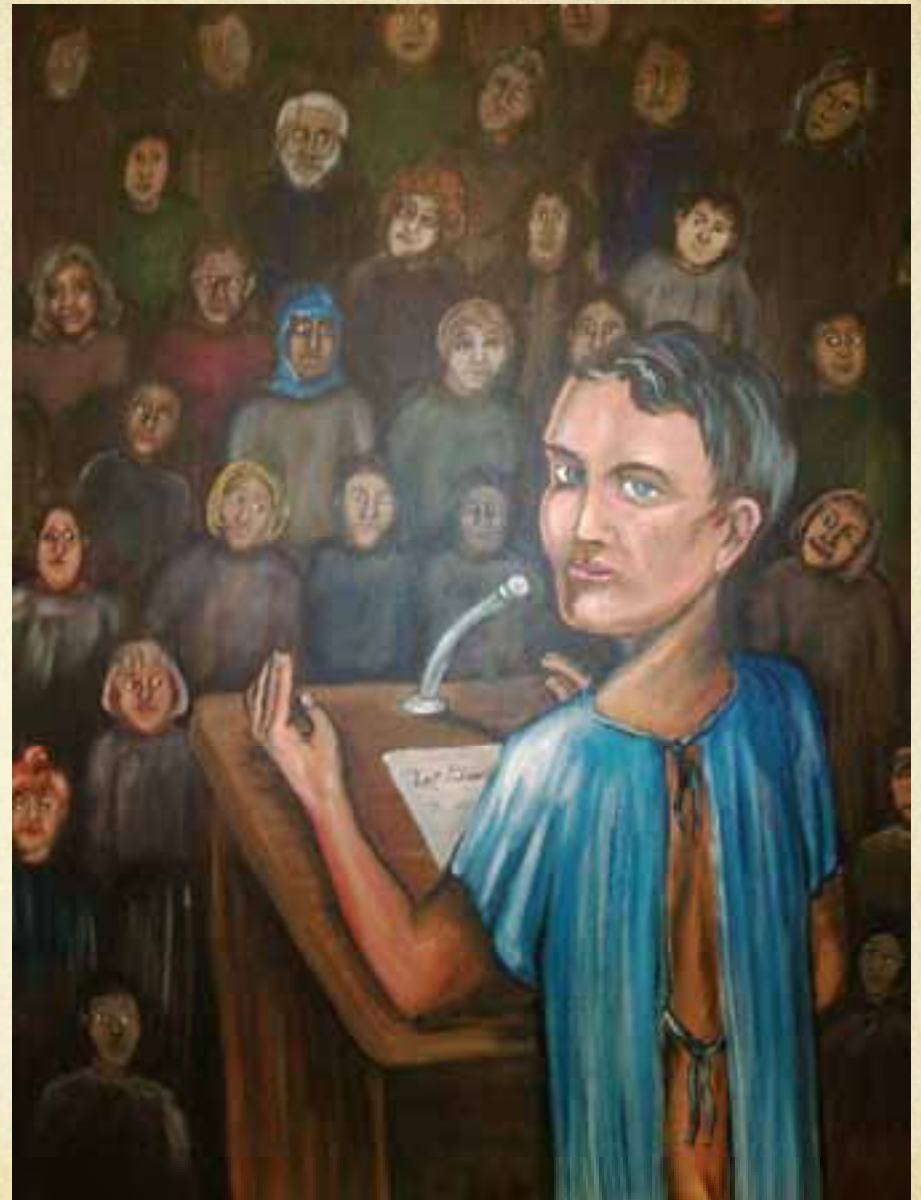
But it shall matter most to our little ones as they reap the benefits of wisdom from those who have gone before. And the reward will be the greatest, if whilst helping the multitudes we focus on the individual.

# Let Patients Speak

We must encourage every committee, sub-committee, and hospital board, to actively recruit and include patients in every aspect of the care process from design to implementation to resolution.

Noting about us without us.

From the exam room to the board room.







Thank you for listening.

It is this important.