

Consumer Advisory Group

Highlights of the Conference Call focused on member experiences with needing, seeking, and using quality of care indicators and information

August 27, 2014
Revised August 29, 2014

Participants

- Lydia
- Craig
- Poppy
- Arthur
- Kim
- Kathy

Ground Rules

- Poppy will facilitate the stories and discussion
- Craig will provide facilitation support, keep time, and take notes
- Make room for all questions and comments
- Follow facilitation instructions

Agenda

1. Opening
 - Welcome
 - Introductions
 - Agenda and Ground Rules
2. Stories and Clarifying Questions
3. Discussion
4. Wrap-Up

Stories

- Kathy
 - The reason for my work is because of my father's tragic healthcare experience
 - Our family was not informed about a MRSA outbreak at his hospital and such information could have saved his life
 - I believe that patients have a right to know what providers know
 - In 2011 I was well connected with patient safety advocates and became a patient myself
 - Upon the advice of my network of patient safety advocates I tried to assess safety at three different New England hospitals
 - I found this very confusing because hospitals all use different grading systems and few use outcome measures
 - The best rating systems lean heavily on quality data, such as:
 - Leap Frog
 - Consumer Reports
 - We have a great opportunity in Maine to make safety information more available
 - Patients have a right to know about safety of providers
 - Process Measure:
 - Focuses on a hospital's compliance with practices that research has proven to be effective
 - The problem is that, for a good outcome, it takes so much more than just a single process. It takes a "culture of safety."
 - Patients need to know that the staff is going to do whatever is needed to keep the patient safe
 - Outcome Measure:
 - Assess whether facilities and providers have succeeded in lowering infection rates
 - Outcome measures are more difficult to validate but are more important to consumers
 - Even outcome measures can be deceiving because they often don't include infections that has occurred after the patient has left the hospital
 - Kathy's Story
 - Kathy used Healthgrade to assess physicians when trying to select a physician to help her with her uterine cancer.
 - Eventually Kathy made a choice based on transparency – not all hospitals were willing to provide her with rates on infections

- We need more detailed data collected and broader reaching data for easy use by patients/consumers
- Wouldn't be great if one could look up, for a specific procedure, the outcomes of particular physicians and particular hospitals?
- Poppy
 - I needed to find a new primary care doctor and tried to find information on which doctor would be best for me
 - Another time I needed an ear, nose, and throat doctor
 - I went to the following websites
 - MainePatientExperienceMatters
 - Seems like a good website but many practices are not listed and many that are listed don't have complete information (all the fields filled in)
 - Lack information about specific doctors at a practice
 - GetBetterMaine
 - Several fields not filled in
 - Lack information about specific doctors at a practice
 - Consumer Reports
 - Really like the way it's set up to report on hospitals
 - Problems with this site
 - Need a membership to access it
 - Just deals with hospitals and not doctors
 - The websites are good at showing what health care networks are available
 - Poppy will send around a report
- Arthur
 - A close friend came down with cancer and she wanted choices but could not find adequate information to make informed choices, particularly about what happens without treatment
- Kim
 - Kim was caring for someone with autism who developed Mono at 8 years old and the care-giving agency pulled away and Kim had to do the care all by herself. Kim had trouble getting him to the doctor's appointment. The doctor's office suggested using an ambulance but Kim thought that would be an abuse of the system.
 - By that time Kim could get the child transported he needed intensive care. If Kim had a primary care physician who was more proactive and in touch with community resources (integration with the community), this situation might have been avoided.

- Kim felt alone. She was given the sense that “this is my problem,” that is, getting the child to the doctor. The doctor’s office didn’t seem to care that she couldn’t move the child.
- Kim now realizes that it’s critical for the providers to work as a team and she has a really good team in place.

Comments on the Stories

- It’s really hard to find a practice that is accepting patients AND learn about specific doctors
- It would be really interesting to see MRSA data by demographics to see if there are differences by age or other demographic characteristics
 - There was a study published in Maine in 2012 that determined that already known MRSA high risk patients (from nursing homes or hospitals in the past 6 months) were in fact high risk patients
 - We do know that the elderly are more susceptible to MRSA and other infections
- It would be good for people to be able to see which doctors make house calls

Closing Comments

- The sharing of stories today was very communicative and useful and appreciated
- If we were more systematic about using stories within the health care system, staff might be much more motivated around quality
- The stories are absolutely integral to quality reporting and quality measures
- We have been talking about “quality of care,” but many mental health consumers on Mainecare are just looking for “care.”
 - On Mainecare, many of us don’t have ANY options
- We should all consider a single-payer system
- It would be good to see which doctors and which practices take Mainecare
- We want to hear more and we will try to figure out how to do that
- Thanks to Poppy for initiating and facilitating this call
- Thanks to everyone for participating