Do We Want to Know about patients’ perceptions of care?
Insights from implementation science

Kathleen Mazor EdD
Meyers Primary Care Institute
University of Massachusetts Medical School
Disclosures

- Grant support

AHRQ 4R18HS022757  Detecting, Addressing and Learning from Patient-Perceived Breakdowns in Care, Kathleen Mazor, PI

AHRQ K08HS024596  Patient-Perceived Breakdowns in Care: Informing Physician Responses and Improvements in Healthcare Delivery  Kimberly Fisher PI
As many as 1 in 4 patients experience a care breakdown

- Many do not make their concerns known
  - Worry about impact on care
  - Systems for reporting not obvious, easy
  - Suspect it will not make a difference
  - Desire to focus on getting well
  - Don’t want anyone to “catch heck”
Why encourage patients to report

- Patient insights could lead to better care
  - For reporting patient
  - For future patients
- If we don’t know about patients’ concerns, we can’t correct misperceptions
Current systems are inadequate

- Emerging reporting systems have limitations
- Active, intensive, multi-modal outreach is necessary
- Real-time responses to “fix” wrongs, and processes to prevent recurrences also needed
We Want to Know

Goal

Patients and family members who have concerns about care find it easy to express their concern and get a response.
The Vision

- Campaign materials get the message out to patients and family members
- “Outreach” interviews screen for concerns
- Message is reinforced by staff and providers on the unit
- Patients & family members utilize 800#, website, email
- WWTK specialist responds to concerns engaging other team members as needed
The Reality

- **Campaign**
  - delayed, limited, uncertain reach
- “Outreach” interviews screen for concerns
  - easier than anticipated!
- **Staff and providers reinforce message**
  - delayed; questionable reach, fidelity
- **Patients & family members initiate reporting**
  - few use; uncertain awareness
- **WWTK specialist responds** to concerns
  - Yes, with caveats
Implementation Science

- **Adoption**: the decision of an organization or a community to commit to and initiate an evidence-based intervention

- **Implementation**: the process of putting to use or integrating evidence-based interventions within a setting

- **Sustainability**: the extent to which the intervention delivers its intended benefits over an extended period of time after external support ends

Adoption... the decision of an organization or a community to commit to and initiate an evidence-based intervention

- A promise is not a decision
  - Site investigator and 1 leader = limited influence
- Priorities are critical, vary over time, and conflict
  - System-level vs hospital- vs unit-level
  - Provider and patient level
- Things change....
  - Reality at the time of the promise differs from reality when the application is funded.
Implementation...the process of putting to use or integrating evidence-based interventions within a setting

- Implementation required a vehicle
  - Made possible by embedding in another initiative
  - Not the vehicle originally planned
  - Significantly delayed

- Adaptation was inevitable
  - Systems, hospitals, providers, adapted the training, message, materials
  - Tracking was challenging to impossible
Sustainability... the intervention delivers its intended benefits over an extended period of time after external support ends

- Leaders (system- and hospital-level) like the program
- But many unanswered questions
  - Who will pay for it? What will they pay for?
  - Who will “mind the store”?
  - What happens when there is a new initiative?
What we learned

- Be wary of promises
- Stakeholders at different levels have different (and possibly conflicting) motivations, priorities, constraints...
- Distance makes everything harder
- Documentation, tracking is critical (and hard)
- Adaptation is inevitable
- Relationships are important!
Thank you

Kathleen.mazor@umassmed.edu