The Practice of R-E-S-P-E-C-T... find out what it means to you

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Disclosures

Dr. Sokol-Hessner is Faculty at the Institute for Healthcare Improvement for the Conversation Ready initiative that aims to improve the reliability of advance care planning for seriously ill patients
Learning Goals

• Recognize the central role that leadership engagement plays in successful implementation and strategies for achieving a culture that promotes dignity and respect

• Practice using a novel framework for capturing, assessing, categorizing and learning from non-physical harms from disrespect
  – Apply the RCA^2 framework methodology

• Discuss the role of Patient and Family Advisors in building a culture of respect

• Analyze institutional readiness for assessing harms from disrespect
Introductions

• Pat Folcarelli
• Lauge Sokol-Hessner
• Barbara Sarnoff Lee
• Frank Federico

What are your roles?
Raise your hand if...

• Your patient safety, risk management, and patient relations departments are integrated?

• You apply a “just culture” algorithm after harm events?

• You have a committee that focuses on the patient experience?
  – What is its relationship to the quality/safety committee structure?

• You feel that others in your organization don’t recognize or understand the problems with the patient/family experience?

• You have Patient Family Advisors within your organization?
<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Presenter</th>
</tr>
</thead>
<tbody>
<tr>
<td>1p-1:15 (15min)</td>
<td>Introductions and Welcome</td>
<td>All</td>
</tr>
<tr>
<td>1:15-1:35 (20min)</td>
<td>Disrespect in Healthcare</td>
<td>All</td>
</tr>
<tr>
<td></td>
<td>Breakout: What’s your experience?</td>
<td></td>
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<tr>
<td>1:35-1:45p (10min)</td>
<td>BIDMC Approach to Preventable Harm</td>
<td>Sokol-Hessner, Folcarelli</td>
</tr>
<tr>
<td>1:45-2:45p (1 hr)</td>
<td>Tackling Non-Physical Harm: RCA^2 approach</td>
<td>Sokol-Hessner, Folcarelli</td>
</tr>
<tr>
<td></td>
<td>Breakout: Describing and Categorizing Cases</td>
<td></td>
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<tr>
<td></td>
<td>Breakout: Prioritizing Using Severity and Risk</td>
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<tr>
<td>2:45-3p (15min)</td>
<td>Break</td>
<td>--</td>
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<tr>
<td>3:15-3:30p (15min)</td>
<td>Reflections on Assessing Cases</td>
<td>All</td>
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<tr>
<td></td>
<td>and Pivoting Prospectively</td>
<td></td>
</tr>
<tr>
<td>3:15-4p (45min)</td>
<td>Engaging Patients and Families in Preventing Future Harm</td>
<td>Sarnoff Lee</td>
</tr>
<tr>
<td>4-4:30p (30min)</td>
<td>Leaving in Action</td>
<td>Federico</td>
</tr>
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</table>
Case 1

An 85 year old man who is an inpatient in the hospital with pneumonia suffers a fall in the early evening. The team caring for him obtains x-rays and discovers he has fractured his hip. No one calls the family to let them know about the fall. The first notification to the surrogate decision maker (son) to let him know about the fall is from the orthopedic surgeon calling to get operative consent for repair of the broken hip. There had been no notification to the family about the fall or the subsequent x-rays. The family is very upset.
Case 2

A patient posts this on the hospital’s Facebook page. “Ok...I have surgery scheduled today and the paperwork says check in @ 5 am. I wake at 3:30 to make the 1 hr. drive from Cape Cod only to learn that one can never check in B4 6 am?? The staff here states it is a little trick they do?? Hope surgery doesn’t have any little tricks or surprises!” Upon investigation it’s discovered that the surgeon’s office staff has been telling patients to get there early as the traffic in Boston is terrible and a lot of patients scheduled for the first case of the day arrive late.
Case 3

A patient had a procedure that required her to stay overnight. She was in a two-person room. Her doctor came in to talk with her about how the procedure went and mentioned the fact that she had HIV in his description of her condition. While the patient already knew this, the doctor spoke loud enough for the roommate to hear. The roommate yelled, “I am not going to share my room with an AIDS patient!” The patient felt her privacy was violated, and was very upset.
Case 4

A patient dies unexpectedly at BIDMC and the BID-network PCP is not notified. A week later, the PCP learns of the patient’s death from his bereaved wife when she calls the PCP’s office with questions. The PCP has cared for the patient’s family for many years so knows them very well. The patient’s family has been grieving deeply and the PCP would have wanted to support them during that time. The PCP notes this is not the first time this has occurred; she is quickly able to name two other patients who received primary care in her clinic and died in the hospital but the primary care physicians were not notified.
Case 5

A patient and her sister come to an appointment with an oncologist. The patient is greeted in the clinic and placed in the room by a medical assistant. 35 minutes later the patient’s sister comes out to ask about the delay in being seen. It is then discovered that her oncologist is not in the clinic that day. When the sister asks how this could happen, a staff member responds by saying “It’s not my job to schedule appointments.” The patient takes her care to another hospital.
Case 6

An inpatient being taken in for a procedure is asked to remove his wedding ring, which is a family heirloom that belonged to his now deceased father. A staff member takes the ring and says he will “lock it up.” When the patient awakens from his procedure no one remembers who took the ring, and can not be found. The heirloom is lost and never recovered.
Taking a new perspective

A medical problem was misdiagnosed: 59%
Mistake was made during a test, surgery, or treatment: 46%
Received a diagnosis that didn't make sense: 42%
Were not treated with respect: 39%
Were given wrong instructions about follow-up care: 29%
Were administered the wrong medication dosage: 28%
Received treatment that was not needed: 27%
Were given instructions from different providers: 24%
Got an infection after a hospitalization or treatment: 24%
Received the wrong medication from a doctor: 18%
Test results were lost, delayed, or not shared: 17%
Received the wrong medication from a pharmacy: 9%
Fell down or out of bed: 8%
Got a bed sore: 8%
Accidentally took too much medication: 5%

Percent of adults with medical error experience who say each happened: 0% to 100%
Table breakout: Types of disrespect

Take 5 minutes to discuss:
What types of disrespect do patients suffer in your institution?
How do you hear about those events, and who handles them?

Then pick someone to report back from your table
Taking a new perspective

Harm can be...
- Physical
- Emotional, psychological, social, behavioral, financial

“Non-physical” harm is prevalent and matters
- We should treat such harm with the same rigor we apply to physical harm
  - Utilizing existing institutional resources and processes

Many ways to learn about where improvements are needed...
- Reportable measures
- Adverse event analysis
- Patient-family advisors

Experience with physical harm

~7000 incidents reported each year
Preventable harm at BIDMC

In 2007 we stated a goal:

“eliminate preventable harm by January 1, 2012”

Preventable: standard of care was not met, or there are reasonable improvements that would decrease the likelihood of a similar future event

Spoiler alert...

...we didn’t get to zero!
Experience with physical harm

Severe and “preventable”

# of incidents per year

~7000

~150

43
## Preventable harm dashboard

<table>
<thead>
<tr>
<th>Category</th>
<th>2nd half 2014</th>
<th>1st half 2015</th>
<th>TOTALS</th>
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<tbody>
<tr>
<td>Avoidable Cardiac Arrest</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Bloodstream infections</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Ventilator Associated Pneumonia</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Falls with injury</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Surgical Site Infections</td>
<td>6</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>All Other Harm (10 categories)</td>
<td>12</td>
<td>15</td>
<td>27</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>43</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Experience to date

Preventable Harm Events By Category, 2008-2015, in Half-Year Increments

# of events

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Avoidable Cardiac Arrest</td>
<td>7</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Bloodstream infections</td>
<td>9</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>9</td>
<td>6</td>
<td>6</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Ventilator Associated Pneumonia</td>
<td>20</td>
<td>16</td>
<td>10</td>
<td>4</td>
<td>4</td>
<td>12</td>
<td>5</td>
<td>0</td>
<td>6</td>
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<td>Falls</td>
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<td>7</td>
<td>6</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
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<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>3</td>
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<tr>
<td>Surgical Site Infections</td>
<td>24</td>
<td>27</td>
<td>35</td>
<td>35</td>
<td>37</td>
<td>33</td>
<td>27</td>
<td>13</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>8</td>
<td>5</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>All other (10 Categories)</td>
<td>18</td>
<td>30</td>
<td>19</td>
<td>8</td>
<td>14</td>
<td>14</td>
<td>17</td>
<td>16</td>
<td>16</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>16</td>
<td>12</td>
<td>15</td>
</tr>
</tbody>
</table>
Why report individual events instead of rates?

Both are useful and important

Stories about actual events are more engaging

• Tangible and aspirational

Rates require a numerator and a denominator

• The numerator is the count of individual events
• The denominator is anyone who was at risk – often hard to determine
Pause

Questions? Reflections?
Experience with non-physical harm

Patient Relations

“Noise”

~3,400 incidents reported each year
Working group

Patient Safety
Health Care Quality
Nursing
Hospital Medicine
Social Work
Palliative Care
Ethics Support Services
Interpreter Services
Communications
Volunteer Services
Community Benefits
Patient Care Assessment Committee Member
Performance Assessment and Regulatory Compliance
Patient-Family Advisors

Definitions

Dignity
Each person’s intrinsic, unconditional value as a human

Respect
The actions that honor and acknowledge dignity
Learning about events

Calls/emails/letters to Patient Relations

Adverse event reports from staff
- Same system for physical harm
- Witnessed or second-hand

Care for those involved in events
- Communication, apology, and reconciliation
- Peer support
Review process

Experienced interdisciplinary group
- Director of Patient Safety
- Manager of Patient Safety
- Patient Safety Coordinator
- Patient Relations specialist

Initially independent, then all together
- Describe and categorize
- Prioritize
## Describing and categorizing

### Key elements of taxonomy | Rationale
--- | ---
Aspects of care | Connect the learning from each case with the group(s) responsible for improvement – a critical part of RCA²
Professional behaviors | Professionals should be held accountable for their at-risk and reckless actions, and supported through their human errors
Contributing system factors | “Every system is perfectly designed to achieve the observed outcomes”; if you don’t change the system, you’ll keep observing the same outcomes
Consequences | Help others – especially organizational leaders – appreciate a “reason for action” and feel a “sense of urgency”
Table breakout: describing and categorizing

Take a few minutes to individually identify the:

- Aspect of care
- Professional behaviors (and apply Just Culture)
- Contributing system factors
- Consequences

Then discuss as a group

If you have time, you can do more cases, just follow the “individual first, group second” format
Prioritizing

Two reasons we need to do this

• Too much to fix, too few resources
  – Too many potential cases, can’t look at all of them in-depth
  – Focus our limited resources by limiting the number of cases

• Challenging to generate consensus about the need for action
  – Lack of consensus $\rightarrow$ limited cooperation $\rightarrow$ limited/no improvement
  – Transparent, formal, risk-based process more likely to lead to consensus
# Prioritizing

1st consider the patient-family perspective

<table>
<thead>
<tr>
<th>Mild</th>
<th>Unfortunate for the patient/family but expected to cause little harm, s/he is not very upset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate</td>
<td>Patient/family is somewhat upset, but it’s not severe or expected to cause long-term harm</td>
</tr>
<tr>
<td>Severe</td>
<td>Patient/family is very upset, and the event is expected to cause severe, lasting harm (significant loss of trust, re-experiencing, depression, avoidant behavior, etc.)</td>
</tr>
</tbody>
</table>

2nd determine risk to organization

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Anticipated harm to future patients/families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rare</td>
<td>Mild: Low, Moderate: Low, Severe: High</td>
</tr>
<tr>
<td>Occasional</td>
<td>Mild: Low, Moderate: Intermediate, Severe: High</td>
</tr>
<tr>
<td>Common</td>
<td>Mild: Low, Moderate: High, Severe: High</td>
</tr>
</tbody>
</table>

3rd put it all together

<table>
<thead>
<tr>
<th>Patient/family perspective</th>
<th>Risk to Organization</th>
<th>RCA² framework methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>Low</td>
<td>Pursue</td>
</tr>
<tr>
<td>Moderate</td>
<td>Intermediate</td>
<td>Pursue</td>
</tr>
<tr>
<td>Severe</td>
<td>High</td>
<td>Pursue</td>
</tr>
</tbody>
</table>
Table breakout: Prioritizing

Take a few minutes to individually:
1. Consider the patient-family perspective
2. Determine the risk to the organization
3. Put it all together to prioritize

Then discuss your ratings as a group

If you have time, you can do more cases, just follow the “individual first, group second” format
Reflections on Assessing Cases

What was that like?

Often limited information about what exactly transpired
• “He said...” and “She said...”
• Especially lacking non-verbal communication

Perceived as “soft”

Both individual and system factors contribute

Important conversations about risk and next steps
Take a 15 minute break!
Experience with non-physical harm

~3300 incidents per year

364

70

After describing, categorizing, prioritizing...

Peer review and cause mapping

Departmental Quality Improvement (QI) Directors

Board-level Quality and Safety Committee

Individual accountability: Just culture
- Human error (slips)
- At-risk behavior (taking shortcuts, drifting from standards)
- Reckless behavior (ignoring accepted standards)

Leader accountability: systems of care
- Monthly action meeting: existing initiative, or do we need a new one?
Pivoting Prospectively

Looking backwards helps us:

• Understand
• Reconcile
• Learn how to prevent future harm
Aspects of care

• Clinic scheduling, waiting
• Introductions
  • Verbal and non-verbal
• Interpretation for limited-English proficiency patients
• Disability accommodations
• Daily inpatient care
  • Washing, transferring, toileting
• Environment of care
  • Noise, cleanliness, etc.
• Pain management
  • Peri-procedural and otherwise

• Peri-procedure management
  • Informed consent, coordination
• Delirium/restraint related
• Privacy
  • Auditory/Information, physical
• Advance care planning
• Adverse event management
• Personal possessions
• Discharge
  • Coordination, timing
• Post-death
  • Timeliness of report of death, autopsy-related
Example: Care after death

Discharge Disposition
Death Pronouncement and Causes of Death
Medical Examiner
Asking about an Autopsy
New England Donor Services (NEDS)
Formerly New England Organ Bank (NEOB)
Notifications
Finalize Report of Death

About Grieving
Grief is the process of adjusting to loss. Most of us will experience one's death at some point in our lives. While grief can be painful, it is important to know that grief is a normal response to loss, and

What to Expect in the First Few Weeks
Soon after the loss of a loved one, many people experience some physical and emotional reactions. These feelings are natural, but they can be overwhelming. Over time, these feelings may begin to fade, but it is important to remember that everyone's experience is unique.

Common Physical Reactions:
- Fatigue
- Weight changes
- Changes in sleep patterns

Common Emotional Reactions:
- Crying or sobbing
- Numbness
- Confusion
- Shock or disbelief

To the family of [patient name]

[address]

[Gty], [state] [zip]

[date]

Dear Family of [deceased patient’s name],

We are writing at this time to let you know that the autopsy results for [patient name] are now available.
They’re on Our Team

Patients and Families as Partners in Quality and Safety

Embracing patient partnership
Mining for Gold

Using patient insights to make meaningful changes
Partnering with Patient/Family Advisors on Respect and Dignity

Advisor Rounding

Privacy

• “Came in through ER and was put on a stretcher for the next 10 hours. The lack of privacy was not a comfortable situation as she has a tracheotomy and clearing it was embarrassing.”

• “PT was sitting on the bed in front of the window and asked to have diaper change done in the bathroom. Aide said it was too crowded in there. Pt. felt that aide was not sensitive to her sense of decency and privacy. Eventually pt was able to get the blinds pulled down.”
Partnering with Patient/Family Advisors on Respect and Dignity – Advisor Rounding

Environment of Care
• Upon arrival, the toilet was dirty and the bathroom smelled of urine. Her roommate's floor was littered with band-aids and other detritus and no one came to clean the floors all day.

Responsiveness and Communication
• After 45 minutes of waiting for breakfast he asked his nurse if it was on its way. Patient felt nurse was rude to him by saying he would have to wait because it's "not a hotel".
• Staff have a conversation in front of her and call her 'she'. As if she is not there. She spoke up and said "my name is xxx".

Personal Belongings
• “The Pt told me that the night that he was admitted, one of the nurses was going through his pants pockets, and when he questioned her, she did not answer him and left.”
Where we started...
Where we started...

Critical Care context

• 77 Adult ICU beds, 6000+ patients/year
• High-pressure landscape with universally present technology
• Complicated organizational structure
  – Physicians: Medicine, Surgery, Anesthesia, Cardiac Surgery, Vascular Surgery, Trauma Surgery, Neurosurgery, Neurology, Cardiology, Emergency Medicine
  – Not just the docs! Nurses, respiratory therapists, social workers, physical therapists, pharmacists, patient care technicians...
• Critical Care Quality landscape
  – Improvements in sepsis care, VAP reduction (>90%), implementation of leading edge information system, central line infection prevention, etc.

• What’s missing from this? The person
How we welcomed families:
Framing the question ...

How can we get better?

- Work with key stakeholders
  - Focus attention on the patient and family at all levels
  - Critical Care Executive Committee
  - Health Care Quality / Director of Critical Care Quality
  - Medical Executive Committee
  - Patient Care Committee / Board of Directors
- Better understanding of our patients’ experience
  - Talk to the experts
  - ICU Patient/Family Advisory Council
- Group of providers working to implement change
  - Work with ICU staff to implement change
  - Critical Care Experience Task Force
Organizational design

**Vets strategy and tactics**
Sets priorities

**Mix of managers and front-line staff**
Develops plans for concrete change
Champions implementation

**Implements and innovates**
Provides feedback

ICU Alumni
(Patient / Family Advisory Group)

Critical Care Experience Task Force
(ICU Providers)

- Nurses
- Physicians
- Social Workers
- Patient Care Techs
- Respiratory Therapists
- Unit Coordinators

Clinical Staff
(Front-line Providers)
Creating the Adult ICU Advisory Council

Candidate Identification
- Exit surveys
- Staff referrals
- Posters/brochures

Screening process
- Survey review
- Discussion with staff
- Personal interviews in collaboration with Social Work

ICU Advisory Council
ICU PFAC
(Intensive Care Patient and Family Advisory Council)

• Council consisted of patient/family advisors and staff members (clinical providers, administrative leaders)
• Members set goals
• Meetings at regular intervals (bimonthly)
• Evening meetings/meal/parking reimbursement provided
• Expectation of one year of service
At the first meeting we asked the PFAC...

What does success look like?

And they said...

- Tangible outcomes
- A few things accomplished and well executed
- Having our voices heard

BIDMC

ICU PFAC
Themes from the First Meeting

Communication
• How can I get the information I want & need, when I need it?
• Who can I trust to give me the “true” information?

Partnership in caring
• Visiting hours
• Too many rules
• How to personalize the care

Environment: Cold, dull, uncomfortable, boring
Waiting Rooms

What could have made your ICU experience better?

It would be better if the ICU waiting rooms weren’t dull, boring, creepy, and dirty.

BIDMC

ICU PFAC
Project: Waiting Room Revitalization

- Project launched
- Funding acquired
- Designer engaged
- ICU PFAC reviews plans and sends designer back to drawing board
From direct PFAC advice the waiting room went from this...
To this....
Family Sleep Room

ICU Family Sleep Room

To find out if this room is available for an overnight stay, please use the black house phone (inside the ICU Family Room) to dial:

x4-4092, between 7:30am - 8pm
x2-9111, between 8pm - 7:30am

Please obtain a sign-out card from the front desk in your unit after you have confirmed the room's availability at one of the numbers above.

When you have obtained your sign-out card, please see the following people to obtain a key:
7:30am-8pm: BIDMC Ambassador, Clinical Center Lobby Desk
8pm - 7:30am: Public Safety, Farr 1.
Families on Rounds

Patients and Families need more direct communication with the team

What if we allow families to participate in multidisciplinary morning rounds?

ICU PFAC

BIDMC
Families on Rounds:
2 Cards Created for Family Members

Communicating with the ICU team

Communication with you is a very important part of our job here in the ICU. Different families prefer different amounts of information: some families like to know a lot of details, others don’t. Here are some ways that we communicate with you:

**Ask your nurse.** This is often the first, and best, place to start. Nurses in the ICU take care of 1 or 2 patients at a time. They spend a lot of time with their patients and know all the details of what is going on.

**Ask your doctors.** There is a team of ICU physicians caring for your family member. We have at least two doctors here 24x7. The best time to speak with them is usually in the afternoon, between 2:00pm and 5:00pm.

**Ask your social worker.** Social workers have helped other families with issues like: coping with the challenges of a loved one being ill and hospitalized, resources such as local lodging or how to get extra help at home, concerns related to alcohol or substance abuse, etc. Ask your nurse to call your social worker.

**Schedule a family meeting.** A family meeting is a time for you to meet with the care team and review what’s going on. It is protected time for communication about where we’ve been, where we’re going, and what to expect.

**Join us on Rounds.** We are trying something new. Usually, rounds include just the doctors, nurses, and other health care providers. We are piloting a program to include families who want to participate as part of rounds. If you think you might be interested in attending, read the information below explaining what rounds are and let us know if they are of interest to you.

**Rounds in the ICU**

**What are Rounds?**
During “rounds” your family member’s nurse, the ICU physicians, and sometimes the respiratory therapist, pharmacist, or other members of the team review and discuss all aspects of your loved one’s care for the day.

**When do rounds take place?**
8:30am – 1:00pm, seven days a week.

**When will the team round on my family member?**
The order of rounds varies daily based on patient needs, so we can’t predict exactly what time rounds on your family member will take place. If you tell your nurse you want to attend, we will make every effort to make sure we find you before we start rounding on your family member.

Joining rounds? Let us know!

- [ ] Yes, please include me in rounds.
- [ ] No, I’m not interested in rounds.
- [ ] I’m not sure*

*If you check “I’m not sure”, we will check in with you to answer any questions or concerns.

Please return this card to your nurse.
Leveraging the patient voice: Our Patient and Family Advisory Councils

Hospital-wide council launched 2010

Councils in multiple sites
- Critical Care
- Primary Care
- Psychiatry
- Neonatal ICU
- Universal Access

Year over year growth – in 2015 there were 93 advisors participating in over 6 activities each, including:
  - Advance care planning
  - Environmental sustainability
  - Respect and Dignity Initiative
  - Welcome video
Patient and Family Engagement

PFAC
@100 active Patient and Family Advisors

5 Patient and Family Advisory Councils; 14 ongoing committees with embedded advisors; countless other contributions

Each advisor participates in an average of 13 activities (meetings, focus groups, events, trainings, or e-advising activities) per year

10% of all Advisor contributions involve participation on an advisory council

40% of Advisor contributions involve participation on an ongoing committee

50% of Advisor contributions involved e-advisor requests, focus groups, retreats, staff education, or other short-term activities
Beyond the PFACs: Advisors...

- Are members of standing committees
- Consult on space design projects
- Consult on quality improvement projects
- Present at conferences, “rounds”, and staff trainings
- Provide feedback for web and print materials
- Participate in focus groups and research projects
- Round on patients in the hospital
<table>
<thead>
<tr>
<th>Focus Groups</th>
<th>Events</th>
<th>Research</th>
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<tr>
<td>Inpatient portals</td>
<td>Department of Medicine QI retreat</td>
<td>Inpatient Consultations study</td>
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<tr>
<td>Food services</td>
<td>Perioperative Surgical Home retreat</td>
<td>MyICU – Moore Grant</td>
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<td>End of life planning information</td>
<td>MACRMI Forum</td>
<td>OpenNotes Safety Study</td>
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<td>OurNotes</td>
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<td>Silverman Symposium</td>
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<tr>
<td></td>
<td>Critical Care Grand Rounds</td>
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Partnering with Patient/Family Advisors on Care of the Family After Death and Dignity

Care of the Family After Death
- Comfort Cart feedback
- “About Grief” handout
- Autopsy information sheet

Advance Care Planning
- Conversation Ready Committee
- Focus Groups on patient information
- Simulation trainings on “code conversations”
- PFAC discussions
Advisors

Assist with space design projects

• Design of a new waiting area for family members of surgical patients
• Provided feedback about privacy curtains for renovations
• New Inpatient building
Advisors

Consult on Improvement Projects Across the Medical Center

Respect and Dignity

- Perioperative Surgical Home
- Staff uniforms in inpatient areas
- Bereavement support pilot project
- Bedside nursing change-of-shift pilot
Advisors

Edit, and provide feedback, testimonials, and photos for written and web materials

- Employee code of conduct
- HCA welcome packet
- Social Work brochure
- End of Life planning / MOLST packet
- BIMDC portal article about patient safety
- My Health Journey – Leaving BIDMC webpage
- Patient and Family Engagement e-newsletter
- Radiology postcard
- Mammogram poster
- Diabetes packet
- My ICU
Advisors

Provide Feedback on Customer Service Standards

- Communication about “what to expect”
- Wait times
- Phone etiquette
- Cultural sensitivity
- Interpreter services
- Preferred name
- Taxi signage
Advisors

Teach staff and providers

- Participated in nurse competency training videos
- Participated in Ebola video
- Presented at Schwartz Center Rounds
- and Critical Care Grand Rounds*
- Were featured in several Silverman posters
- “You Know Me” video shown at every staff orientation
Meet with BID Plymouth PFAC leaders
Consult with Sloan Kettering
Complete survey for nationwide study of Patient and Family Engagement
Member of HCFA PFAC Steering Committee
Participate in Betsy Lehman Center workgroups
Attend conferences

Are ambassadors of BIDMC Patient/Family Engagement

Health Care For All
Critical Care Grand Rounds
An ICU stay through the eyes of the patient
Patient and Family Advisors...

- Provide valuable feedback to inform our system
- Identify areas for improvement
- Prevent unnecessary spending / cut costs
- Help us assess patient experience in real time
- Support quality and safety efforts
- Foster employee engagement
- Educate and ‘socialize’ providers and healthcare staff
Lessons learned

• Creating a family-centered model of care requires institutional buy-in and support (financial and personnel)
• Development of a patient and family advisory council requires careful planning and execution
  …and a willingness to relinquish some degree of control
• Having a consistent set of metrics allows change to be tracked over time
• Not all well-intentioned interventions are successful
  …learn from flawed implementations, stay humble
• It takes a village…
MUST HAVES...

- Commitment from the top. This is essential.

- A strong belief that this is important... it’s not just a slogan.

- Appropriate resources, both financial and designated personnel
Providing respectful, person centered care means doing the work *WITH* patients and not *For* patients
“Don’t let fear cause you to avoid engaging patients; be present, value it. Change won’t be effective if it gets delegated, you have to be part of it. At the end of the day it has to be meaningful, it has to be about patients.”

Marsha Maurer
SVP, Patient Care Services, Chief Nursing Officer, BIDMC
Where we’ve been today...

- Recognizing non-physical harm and disrespect
- RCA^2 approach to categorizing and assessing risk
- Patient-family engagement integral to improvement

Where you’re going...

Leaving in Action
Thank you for your attention!

Questions?

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