Listening to the Voice of the Patient

Singapore Health Management Congress 2012
Janet E. Porter, PhD
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Today’s Objectives

- Discuss Dana-Farber’s history and approach to ensuring that patient and family voices are heard
- Explain how patient and family voices have transformed patient care at Dana-Farber
- Challenge you to think about how you can incorporate the patient voice in everything you do
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Dana-Farber Cancer Institute

- $1 billion Harvard cancer center, 40% research, 60% patient care

- Adult care provider in partnership with 700-bed Brigham and Women’s Hospital (ranked # in adult oncology)

- Pediatric care provided in partnership with Boston Children’s Hospital (ranked #1 in pediatric oncology)
Early History of Patient Engagement

1995
- Stimulus for change: Death of two patients from medical error

1996-97
- Integration of DFCI and Brigham & Women’s Hospital
- Patients and families voice concerns

1997
- The path to listening to the patient voice: Gradual partnering

1997-98
- With support of leadership and Institute for Family-Centered Care, Patient & Family Advisory Council is formed
The Path to Listening to the Patient Voice

- Patient surveys were not enough
- “Town Meeting” with staff, patients & families
- Support from Board, CEO, COO, CNO, CMO
- Decision to start small
- Began by populating existing committees working on the integration of the hospitals with patients and family members
- Additional areas of patient & family involvement:
  - Patient education
  - “Glitch rounds”
- Leadership courage to create a culture shift despite tension
- Institute engaged help from Institute for Family-Centered Care
Adult PFAC Mission

The Adult Patient and Family Advisory Council is dedicated to assuring the delivery of the highest standards of comprehensive and compassionate health care by Dana-Farber/Brigham and Women’s Cancer Center. We do this by working in active partnership with our health care providers to:

- strengthen communication and collaboration among patients, families, caregivers and staff;
- promote patient and family advocacy and involvement;
- propose and participate in oncology programs, services, and policies.
Role of PFAC Active Member

- Provides feedback, guidance, updates at monthly meetings
- Serves as voice of the patient on standing hospital and board committees
- Participates on working groups and projects
- Generates goals annually and prioritizes initiatives
- Maintains confidentiality
  - Volunteer Orientation
  - HIPAA Training
  - Sign same confidentiality statement as staff members
- Continually provides expertise of the patient experience
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Yawkey Center Design Principles

The Center will be a hopeful, welcoming place that:

- Promotes personalized, multi-disciplinary, safe, respectful, compassionate cancer care for patients and families, in a healing environment, as envisioned in 2020
- Stimulates translation of research into care of patients
- Optimizes flexibility and utility of space
- Streamlines flow of patients and materials, minimizing wait and treatment times
- Fosters productivity and collaboration of staff
- Creates a new public presence and signature image and access to Dana-Farber
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Envisioning Cancer Care in 2020

Leading Edge Research
Diagnosis & Treatment
Envisioning Cancer Care in 2020

Leading Edge Research
Diagnosis & Treatment

Compassionate,
Respectful, Patient
Focused Care
Envisioning Cancer Care in 2020

- Leading Edge Research
- Diagnosis & Treatment
- Compassionate, Respectful, Patient Focused Care
- Operational Efficiency
Envisioning Cancer Care in 2020

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Ideal Patient Care
Envisioning Cancer Care in 2020

Increasing Consumerism

Leading Edge Research
Diagnosis & Treatment

Operational Efficiency

Genomics, Personalized Health Care

Technological Advances

Compassionate, Respectful, Patient Focused Care

Changing Reimbursement

Continuing Shift to Outpatient Care

Ideal Patient Care

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### Key Assertions About Care in 2020

#### Leading Edge
- All patients will receive highly customized care.
- All patients will be subjects of research studies.
- Cancer care will re-aggregate along genetic/effective treatment lines and away from tumor site.
- Treatments will be based on pathways rather than histologies and will be increasingly precise.
- Super-sub-specialization will necessitate involvement of more people in the care of patients.
- Assessment of treatment efficacy will be increasingly ‘real-time,’ and will shift from anatomical to biological measures. Functional imaging will play a key role.
- Cancer risks will be identified with greater precision and even earlier in a patient’s life, until cancer care begins in general pediatrics? Neonatology?
- Expert pathology and imaging will become even more essential to getting the diagnosis and treatment right.

#### Efficient
- All patient information will be available to the appropriate parties at all times.
- Information on patients’ whereabouts will be available at all times, so that flow can be managed effectively.
- Waiting will be minimized throughout the system.
- Patient flow will move in a progressive fashion – not back and forth.
- Patients will have the option/ability to do more offsite in advance of their visit.
- Fewer, more flexibly designed exam rooms (i.e. universal rooms) are preferred over more, somewhat compromised exam rooms.
- Staff efficiency will be driven by adjacency of space, supportive technology and streamlined processes.
- Care will be most efficient if delivered by disease centers with oncologists, surgeons, radiation oncologists working as a team for each patient.

#### Patient Focused
- We will provide a comfortable, safe, healing environment that respects patient privacy and choice.
- We will provide personalized service and clear, simple processes to optimize the experience for patients and families.
- Relevant, accurate information regarding patient care and processes will be communicated effectively among members of the care team, as well as to the patient and family.
- Patients always will have the flexibility to seek information from a person or appropriate technology.
- The patient experience will be seamless regardless of care site, so inpatients and outpatients feel that they are being cared for by one organization.
Patients Were Engaged in Every Stage of Planning and Design

- Architect Selection
- 2020 Process: design assumptions
- Trips to other hospitals
- Patient Flow/Centralization
- Floor Planning
- Center for Patients & Families
- Information Kiosks
- Healing Garden
- All furniture, fixtures, equipment, and finishes
- Communication
- Planning the Move
The Patient Experience Committee: A True Partnership between Staff and Patients

- Co-chaired by COO and a member of PFAC
- Created teams of PFAC members who sat on all Yawkey planning “live-in” workgroups (pharmacy, phlebotomy, clinical care, scheduling, etc.)
- PFAC teams each consisted of a senior & junior PFAC member
- Met monthly to report on progress of “live-in workgroups”
Create Patient Experience Document

- Collect patient experiences from patients, families, patient-family relations department, social work, etc.
- Document findings
- Categorize experiences
- Highlight problems/issues in need of resolution (e.g., difficulty of getting stretcher patients safely to MD offices as emergency walk-ins)
- The Patient Experience Core Document became the basis for all operational success metrics
Solutions/Ideas Selected

- Prioritized “critical success metrics” for Yawkey
- Brainstormed “optimal” call management systems with recommendations for pilot and roll-out
- Reviewed itinerary/flow for new patients
- Participated in RTLS (Real-time Locator System) pilot workgroup to improve patients’ wait time experience
- Served as “mock patients” during staff training & transition to Yawkey
Patients’ voices transformed Yawkey planning and design. They answered key questions:

- Should the services go to the patient or should the patient go to the services?
- Should exam and infusion be together or separate?
- Should the windows be in exams, infusions or waiting?
- How can the exam rooms be safer?
- What is important in infusion?
- How can we be as welcoming as possible for new patients and families?
- How can the space exude comfort and healing for all patients and families?
Key Question:
Should services go the patient or the patient go to the services?

Answer:
“Don’t stick me in an exam room waiting for staff to come to me. We’d rather go to the services.”
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Key Question:
Should exam and infusion be on different floors or the same floor?

Answer:
“We want all the experts for our care together. Put infusion and exam on the same floor.”
Key Question: Should the windows be in the exam, infusion or waiting areas?

Answer: “We want the windows in infusion and in the waiting areas – which should feel like living rooms.”
Key Question: How Can the Exam Rooms Be Safer?
Key Question: What is important in infusion?
Answer: “We want to be comfortable and we want our visitors to be comfortable.”
Key Question: What do we do to make patients and families feel welcome?
Key Question: How do we create a warm, welcoming, healing place? **Answer:** A healing garden.
**Key Question:** How Can we Create A Warm, Welcoming, Health Place?

**Answer:** “Have Art that Speaks to the Soul”
Key Question: How do we recognize the faiths of all our patients and families?

Answer: “Build a chapel where all faiths feel welcome.”
So what is the outcome of all this patient and family involvement?

• Do the patients really have ideas we haven’t thought of already?
• Doesn’t it take much longer?
• And cost much more?
• And can the patients really agree on what they want?
• Can the patients really provide ideas that make the processes more efficient?
Patient Satisfaction Improves

Press Ganey Overall Patient Satisfaction, DFCI-Longwood

FY 2004 - FY 2012

Singapore Health Management Congress 2012
August 29, 2012
## Yawkey Critical Success Metrics

<table>
<thead>
<tr>
<th>Metric</th>
<th>Start Description</th>
<th>Median (Standard Deviation) in minutes</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valet Drop-Off</td>
<td>Car enter driveway, Pt/ family exit car</td>
<td>Baseline: 4 (2), 1/31: 1 (0), 2/4: 1 (0), 2/14: 1 (0), 2/21: 1 (0), 2/28: 1 (0), 3/7: 1 (0), 3/14: 1 (0), 3/21: 1 (0), 3/28: 1 (0)</td>
<td>Continued minimal wait times</td>
</tr>
<tr>
<td>Central Registration</td>
<td>Apt. &amp; check-in, Start meeting</td>
<td>Baseline: n/a, 1/31: 0 (1), 2/4: 0 (1), 2/14: 0 (1), 2/21: 0 (1), 2/28: 0 (1), 3/7: 0 (1), 3/14: 0 (1), 3/21: 0 (1), 3/28: 0 (1)</td>
<td>Continued minimal wait times</td>
</tr>
<tr>
<td>Lab Services</td>
<td>Apt &amp; check-in, Collect Specimen</td>
<td>Baseline: 16 (20), 1/31: 8 (9), 2/4: 8 (9), 2/14: 7 (8), 2/21: 7 (9), 2/28: 8 (8), 3/7: 5 (8), 3/14: 7 (8), 3/21: 7 (18), 3/28: 9 (16)</td>
<td>Continuing to streamline and standardize processes, Clinic support staff cross-trained to work in all three regions</td>
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<tr>
<td></td>
<td>Pt/ family exit car</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Valet Pick-Up</td>
<td>Car requested</td>
<td>7 (2) 8 (2) 8 (3) 8 (3) 7 (2) 7 (2) 6 (2) 7 (2) 7 (1) 7 (2)</td>
<td>• Consistent performance week-over-week</td>
</tr>
<tr>
<td></td>
<td>Car ready</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Central Registration</td>
<td>Apt. &amp; check-in</td>
<td>n/a 0 (1) 0 (1) 0 (1) 0 (1) 0 (1) 0 (1) 0 (1) 0 (1) 0 (1)</td>
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<td></td>
<td>Collect Specimen</td>
<td></td>
<td>• Clinic support staff cross-trained to work in all three regions</td>
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<tr>
<td></td>
<td>Lab Turnaround – Chem</td>
<td></td>
<td>• Continued improvement over baseline even with the addition of vitals to workflow</td>
</tr>
<tr>
<td></td>
<td>Glucose</td>
<td>39 (48) 26 (28) 32 (34) 25 (30) 16 (31) 29 (30) 29 (34) 27 (27) 26 (27) 21 (25)</td>
<td>• Consistent improvement over baseline led by reduced transportation time</td>
</tr>
<tr>
<td></td>
<td>Collect specimen</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Results available</td>
<td></td>
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<tr>
<td></td>
<td>Lab Turnaround – Hem</td>
<td>21 (13) 16 (11) 20 (13) 18 (11) 17 (11) 19 (15) 20 (11) 18 (15) 16 (10) 17 (10)</td>
<td>• Consistent improvement over baseline led by reduced transportation time</td>
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<tr>
<td></td>
<td>CBC-A</td>
<td></td>
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<td></td>
<td>Collect specimen</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Results available</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pharmacy Turnaround</td>
<td>46 (48) 58 (45) 53 (39) 43 (35) 46 (40) 43 (34) 49 (39) 48 (37) 47 (37) 46 (35)</td>
<td>• Sustained improvement in median and standard deviation reduction</td>
</tr>
<tr>
<td></td>
<td>Apt &amp; check-in</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>First chemo available on floor</td>
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August 29, 2012
Building Outcomes

✓ Yawkey first healthcare building in Boston area to receive LEED Gold Certification from US Green Buildings Council

✓ Yawkey receives numerous national design and construction awards
  ✓ Association of General Contractors (AGC) National AON Build America Award for Construction Management, New
  ✓ AGC Build New England Honor Award
  ✓ Construction Management Association of America (CMAA), New England Chapter, Project Achievement Award for New Building Construction over $200M
  ✓ American Council of Engineering Companies of Massachusetts (ACEC/MA) Silver Engineering Excellence Award
  ✓ Deep Foundations Institute National First Runner-up for the Outstanding Project Award
  ✓ Modern Healthcare Design, Design Citation Award
  ✓ International Interior Design Association New England (IIDA) – Healthcare Project Award

✓ Yawkey is completed ahead of schedule

✓ Yawkey is under budget by $10M on $350M project budget
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Applying This Model

- Have humility – Do you really know what it is like to be a patient in your hospital?
- Understand that listening to patients and families makes your job easier (and more gratifying) than harder
- Because you get it right the first time
- Build a case for involvement from patient satisfaction results, letters from patients, examples of problems
- Leadership support is critical
- Utilize outside resources to build support, help with process
- Have a powerful story about how patient involvement makes a difference
Getting Started

- Start small with one service line
- Engage physician and staff champions; have them nominate grateful patient and family members
- Interview prospective patient and family members; make sure they can be constructive and think beyond their individual story
- Orient those selected to the organization
- Brainstorm issues they would like addressed
- Come with ideas about how they might be helpful
- Jointly draft a document clarifying role of PFAC members
- Develop a policy about payment for services (DFCI does not pay any patients for this support)
- Provide administrative support
Key Lessons

- Patients do want to give back, make a difference for others, are incredibly grateful and committed to your organization. “It’s not about me, it’s about us!”
- It is easier to run a hospital if you have an easy way to get patient and family members’ opinions
- Patients and family members will surprise you with ideas that never occurred to you or contradict your viewpoint, their sensibility
- Transparency works and builds trust
- Self-governance works
- We work for the patients and families
“Courage doesn’t always roar. Sometimes courage is the quiet voice at the end of the day saying, ‘I will try again tomorrow’.”
Mary Anne Radmacher

**courage**