Patients as Partners in Policy and Program Improvement: Myths, Challenges, Opportunities and Rewards

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Learning Objectives

• Understand the role patients can play in your organizations' policy development and program improvement efforts
• Understand what you might need to put in place (commitment/infrastructure) to support effective patient involvement
• Identify ways you might involve patients
  • *ad hoc* work groups
  • standing committees
  • advisory boards/task forces
  • focus groups
Why This Topic?

• Growing interest in incorporation of stakeholders in
  • Organizational leadership, governance, and policy development
  • Program design, implementation, and improvement
• Burgeoning international recognition specifically of the critical role of patients’ voices in improving health-related policies and programs
• Organizations looking for guidance in their efforts to incorporate patients
Incorporation of Stakeholders: Human Centered Design Engineering

“A creative approach to problem solving. It's a process that starts with the people you're designing for and ends with new solutions that are tailor made to suit their needs, preferences, values and outcomes.”

“Start with the user and all else will follow” – Google
Changing Vision of Role of Patient in Clinical Care and Research

- Inclusion improves
  - Feasibility
  - Relevance
  - Communication/dissemination
  - Buy-in/motivation
  - Social and political will
  - Quality improvement efforts
  - Credibility and trustworthiness
Power of Partnerships
Person-Centered Healthcare System

Outcomes important to patients, families and communities

- Care
  - Person-centered care
- Healthcare Services
  - Implementation
- Research
- Policy
- Evidence

Outcomes important to patients/people, families and communities

Person/patient Engagement
“The biggest untapped resources in the health system are not doctors but users. [...] We need systems that allow people and patients to be recognized as producers and participants, not just receivers of systems. [...] At the heart of [co-design], users will play a far larger role in helping to identify needs, propose solutions, test them out and implement them, together.” (Cottam & Leadbeater, 2004, pp.16-22)
Patient Engagement in Leadership, Governance, and Policy Making

- Co-development of:
  - Performance/quality/cost measures
  - Practice guidelines
  - Payment models
  - Regulations
  - Hospital accreditation standards
  - Certification Standards

- Partners:
  - Payers -- CMS, private insurers
  - Purchasers – Employers/Leapfrog
  - Public health officials – CDC
  - Regulators – FDA
  - HIT - ONC
  - Public private (NQF, NAM, PCORI)
  - Guideline developers-Specialty societies
  - Accreditors
  - ABMS
Person and Family Engagement In Program and Policy Development at CMS

- Technical Expert Panels
  - Cost measures
  - Outcome measures
  - Shared decision making measures
- Submit suggested measures
- Comment on Rules
- Provide input during Special Sessions
- Participate in program development
  - Partnership for Patients (Metrics)
  - Transforming Clinical

Purpose:
“To guide the meaningful and intentional implementation of person and family engagement throughout CMS, policies and programs”
NQF Measure Incubator Goals

The Measure Incubator embodies NQF’s mission by providing the quality measurement community with a more efficient environment to develop and test measures that matter.

The goals of the NQF’s Measure Incubator are to:
- Facilitate development of measures that would be more meaningful but are difficult to construct and test, particularly measures that allow for patient-reported outcomes
- Rapidly fill measurement gap areas
- Spur development of electronic clinical quality measures (eCQMs) to take advantage of the data collected through EHRs and to help enable measurement—and improvement—in real time
- Drive outcome-based healthcare measurement that better reflects the voice of the patient and caregiver
- Advance measurement science with making tools and test beds more accessible to address tough challenges in measurement
Person and Family Engagement at PCORI

Engagement in Research as a Path to Useful, High-Quality Research

Proposal Review; Design and Conduct of Research

Dissemination and Implementation of Results

PCORI Advisory Panel on Patient Engagement
Person and Family Engagement at FDA

Advisory Committees

Patient Engagement Advisory Committee

2017 Meeting Materials of the Patient Engagement Advisory Committee

Charter of the Patient Engagement Advisory Committee to the Food and Drug Administration

Roster of the Patient Engagement Advisory Committee

Purpose

The Committee provides advice to the Commissioner or designee on complex issues relating to medical devices, the regulation of devices, and their use by patients. The Committee may consider topics such as: Agency guidance and policies, clinical trial or registry design, patient preference study design, benefit-risk determinations, device labeling, unmet clinical
Patient Involvement in Programs: Improving Quality and Safety in Healthcare Delivery

• Bring real world experience, wisdom and passion

• Identify preferences, values and outcomes that matter most to patients, families and communities

• Identify safety and quality gaps in our healthcare system

• Propose solutions, processes, structures to ensure for safety, relevance and patient-centeredness

• Pursue change with a sense of urgency

• Have the greatest at stake
ABMS and Opportunities for Patient Engagement

ABMS Mission Statement

The mission of the American Board of Medical Specialties (ABMS) is to serve the public and the medical profession by improving the quality of health care through setting professional standards for lifelong certification in partnership with Member Boards.
ABMS and Opportunities for Patient Engagement

In the News

A Current Look at Why Certification Matters

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ABMS and Patient Voice

• New Governance Structure incorporates patient voice
• Revised ABMS Organizational Standards January 2018
  • Standard 2. Leadership and Governance. Number 1.
    • To demonstrate stakeholder representation, Member Boards will document how the public interest is routinely represented and protected, which should include public members or other effective means.
  • Standard 5. Stakeholder Engagement. Number 4:
    • The Member Board should effectively communicate and engage stakeholders such as specialty societies, consumer and patient groups, and/or other health care related organizations in a manner consistent with its stated mission.
The ABP and Public Voice

- Public members on ABP and ABP Foundation Board of Directors (BOD) since 1986
- Increasing numbers of staff/QI consultants with interest, experience, and commitment to patient engagement
- North star=improving health of children and families
- Decision to increase parent representation in Fall 2014
- Addition of one parent to each BOD in January 2015
First Patient/Family Meeting: September 2015

• Attendees:
  • 25 parent/young adult patient representatives
    • Many affiliated with quality improvement networks so experience working with organizations
  • Specialty society leadership
  • ABP leadership
Our Goals and Their Recommendations

- **Our Goals**
  - Strengthen patient and family voice at ABP
  - Garner input and feedback on ABP activities, programs, and strategic initiatives

- **Resulting Actions**
  - Provide communication to patients and families about certification
  - Add patient and family representatives to other committees
  - Establish Family Leadership Advisory Group
  - Host yearly meeting with Patients/Parents on key health care topics
  - Inform strategic planning and projects
ABP and Parent Voice

• Parents need to know what the ABP does and why certification is important
• Parents and patients worked on communication plan highlighting the importance of certification and the value of pediatricians participating in quality improvement activities as part of certification
• [www.mycertifiedpediatrician.org](https://www.mycertifiedpediatrician.org)
HE IS CERTIFIABLY DETERMINED
HE DESERVES A PEDIATRICIAN WHO IS CERTIFIED TOO.
ABP and Leadership and Governance

- On both ABP and ABP Foundation Board of Directors, one public member and one parent
- On 7 major committees, have parent representative
  - Examples: MOC, credentialing, research, new subspecialties
- These parent reps together make up the Family Leadership Advisory Group (FLAG)
- Goals of FLAG in 2018-19,
  - Formalize roles within organization (eg, charge, roles/responsibilities document)
  - Develop orientation materials for both parents and physicians (trainees/diplomates)
Additional Feedback: Key Topics in Pediatric Health

- Changing demographics
- Health care access, costs
- Safety: diagnostic/treatment errors
- Care coordination burdens among multiple caregivers
- Health data transparency
- Transitions to adult care*
- Improving communication between patients/family and caregivers*
- Support QI efforts among parents*
- Public understanding of certification*
- Behavioral/mental health care for children and families*

*=areas are where parents and ABP together can make an impact → informed strategic planning
Behavioral/Mental Health Initiatives

• Improving Pediatric Education and Training
  • Co-hosted meeting with National Academies in April 2018

• Roadmap Project
  • Parent-recommended project focusing on behavioral/mental health needs of children with acute, life-threatening and/or chronic conditions and their families
    • Change package for collaborative networks
    • “Scripts” for health care team
    • Video
    • Dissemination
Roadmap Video https://www.abp.org/foundation/roadmap

To learn more about why families and clinicians are partnering in Roadmap, watch our video, “How Are You Doing?”

To learn more about the Roadmap project, please email the Roadmap Project Team.
Increasing Visibility

• James Stockman Lectureship at the American Academy of Pediatrics (AAP)’s Annual National Meeting
  • 2016: Young adult patient with inflammatory bowel disease
  • 2017: Parents of twins with sickle cell
  • 2018: Grandparent and advocate: children in foster care due to substance use

• ABP 2015 Annual Report highlighted the impact of collaborative improvement networks on patient care and outcomes, including the importance of partnering with patients and families

• ABP Sponsor of Family Voices 25th Anniversary Celebration in November 2017
Making It Work

• Engage leadership
• Develop internal infrastructure for patient engagement: governance, policies and processes
• Provide personal contact with mentor in the organization and others who are playing a similar role
• Provide orientation and capacity building for patients and organizational leaders
Making It Work 2

- Watch power differentials; value each person’s expertise
- Watch out for jargon
- Attend to intent: co-production, mutual benefit, reciprocity
- Use QI principles:
  - Start small and create small wins then spread
  - Steal shamelessly and share seamlessly
What We are Working on Now

- Developing tools to build capacity
- Formalizing roles
- Addressing honoraria/stipends
- Diversifying patients
- Deciding on local versus national focus
Myth #1: This is too much work for my organizations to take on and we already have a lot we are working on.
It Takes Some Effort but Can Be Done

- Leadership commitment to change and innovation (learning organization)
- Patient engagement considered a strategic priority within the organization
- Internal structure for patient engagement (point of contact or department)
- Patient representation on governance
- Budget for patient engagement and honoraria
Myth #2: Credentialing is way too complex for patients to understand.
You Would Be Surprised.

• Do not assume that developing and communicating certification related issues/standards is too complex for the patient community
• Set up a patient engagement advisory panel where they can support one another
• Build capacity building for both patients and policy makers to be effective partners
• Use innovative patient-centered methods when engaging with patients to address “power imbalance” (no jargon)
Myth #3: Patients will lose interest over time.
Keeping Patients Engaged is Similar to Keeping Anyone Engaged.

• Open doors to other policy makers for patient
• Include patients in roundtables and conferences and incorporate in other parts of organization
• Develop avenues for patients to connect with organization such as a dedicated webpage, story banks, newsletters and public comment
• Focus on outcomes that matter to patients, families and communities
• Engage patients early and often and ensure voice is influential in decision making with continuous feedback
• Celebrate and communicate achievements and impact of patient engagement
Myth #4: it’s too hard to find patients who can get beyond their own health issues to think at a policy or program level.
Recruiting the RIGHT Partners

• This is not just an issue for patients but for any stakeholders
• Passion and common interest in topic
• Ability to generalize from their experience to the larger community
• Have been previously engaged in partnerships to solve problems
• Recruit via a “call for interest” or solicitation
• Go where the patients are
Finding Patients: Go to Where They Are

- Quality Improvement/Collaborative Networks
- Clinical care: Hospital Patient Family Advisory Councils (PFACS)
- Research studies/centers
  - Community-based Participatory Research (CBPR)
  - Patient-Centered Outcomes Research Institute (PCORI)
  - Clinical and Translational Science Award Stakeholder and Community Engagement efforts through National Center for Advancing Translational Science (CTSA)
  - Agency for Healthcare Quality and Research (AHRQ)
- Other national patient networks
  - CMS
  - FDA
- Disease specific and broad-based patient advocacy groups (e.g., Family Voices)
Questions and Comments?