A Multidimensional Framework for Patient and Family Engagement: Creating Change in Health Care

NC Institute of Medicine Task Force on
Patient and Family Engagement
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Presentation overview

1. What is patient and family engagement? An overview of the framework
2. What led to the development of the framework?
3. What are promising efforts in patient and family engagement?
4. How can we use the framework?

What is patient and family engagement?
An overview of the framework

Patient Parking
Main Entrance

What is patient and family engagement?

A means of achieving financial incentives

Getting patients to do what they're told

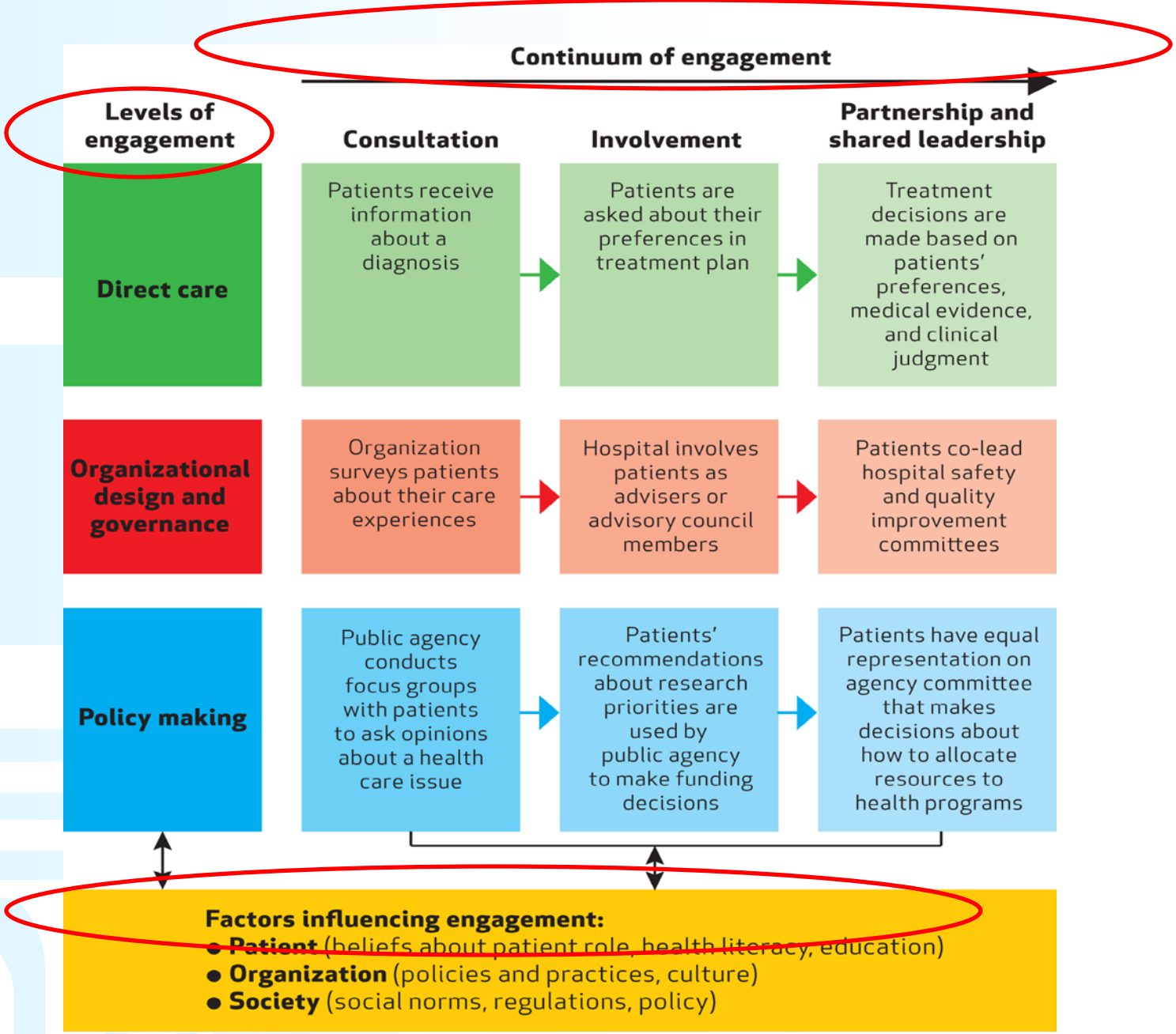
The holy grail of health care

A business and growth strategy

Getting doctors to listen better

The blockbuster drug of the century

An increase in effort and unreimbursed time


Continuum of engagement
Levels of engagement
Consultation
Involvement
Partnership and shared leadership
Direct care
Patients receive information about a diagnosis
Patients are asked about their preferences in treatment plan
Treatment decisions are made based on patients' preferences, medical evidence, and clinical judgment
Organizational design and governance
Organization surveys patients about their care experiences
Hospital involves patients as advisers or advisory council members
Patients co-lead hospital safety and quality improvement committees
Policy making
Public agency conducts focus groups with patients to ask opinions about a health care issue
Patients' recommendations about research priorities are used by public agency to make funding decisions
Patients have equal representation on agency committee that makes decisions about how to allocate resources to health programs
Factors influencing engagement:
• Patient (beliefs about patient role, health literacy, education)
• Organization (policies and practices, culture)
• Society (social norms, regulations, policy)

A working definition

Patients, families, their representatives, and health professionals

Working in **active partnership**

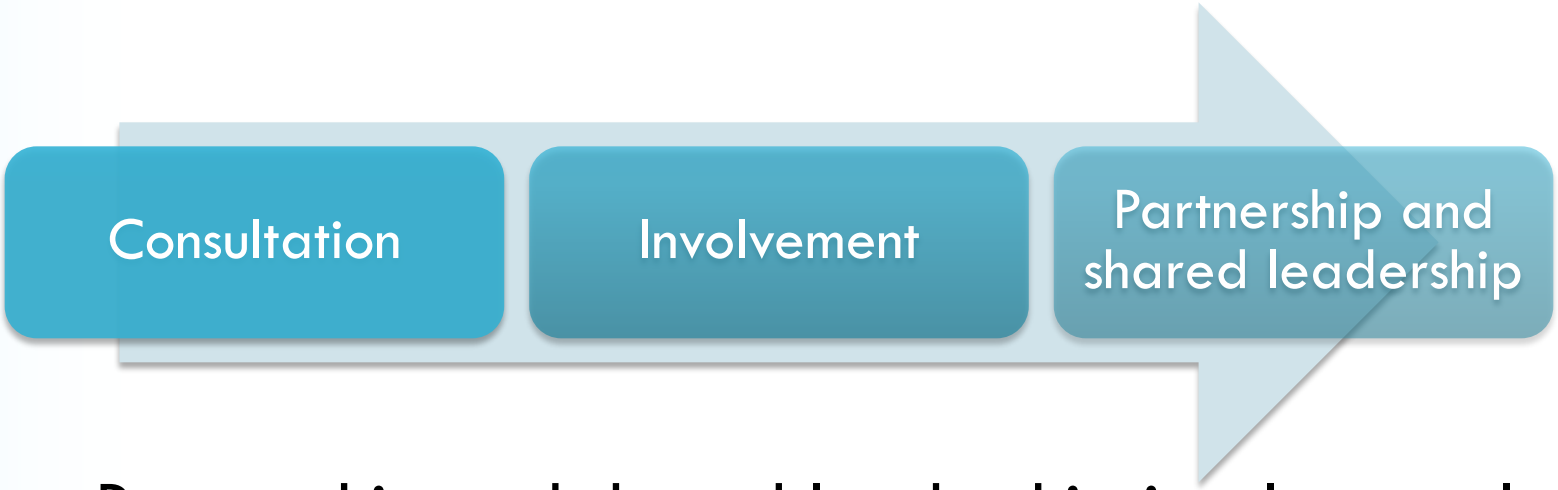
At **various levels** across the health care system

To improve health and health care

Carman et al., "Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies" *Health Affairs*, 32, no.2 (2013):223-231

Who: Patients, families, providers, systems

What: Working in active partnership

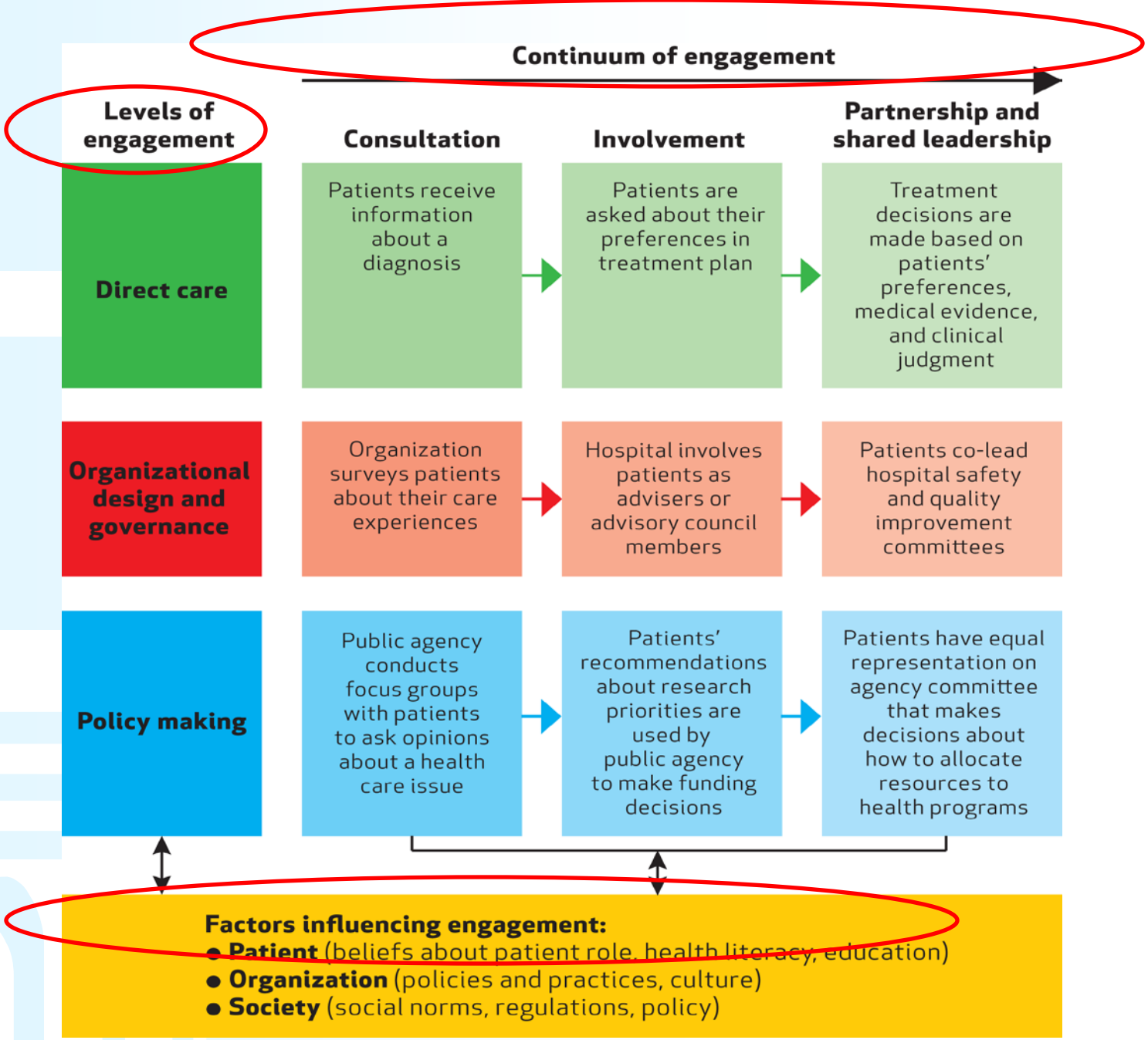


- Partnership and shared leadership involves real culture change, which means:
  - Leadership commitment
  - Provider / patient education
  - Potential changes to workflows, policies, and procedures

Engagement in action?

Engagement in action?

Where: At various levels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Who can benefit from patient and family engagement?

- Patients and families
  - Health outcomes
  - Experience
- Clinicians and health care providers
  - Satisfaction and retention
- Health care organizations and systems
  - Competitive edge
  - Standards, reimbursement, and requirements

What led to the development of the framework?
Evolution and explosion

Evolution of experiences and research

Experiences

- Informing consumers about health options and health care quality
- Developing measures of consumer experiences in different settings

What did we learn?

- Disconnect between consumer and provider experiences and descriptions
- Just providing information or education is not enough

Evolution of experiences and research continued…

Experiences

- Examining system-level changes within organizations
- Comparing methods to get input from the lay public on program and policy decisions

What did we learn?

- Insufficient focus on how system is structured
- Drivers of organizational change and quality improvement
- Few examples of engagement in policy

Explosion of "patient engagement"

Changes in environment

- Affordable Care Act
- Changes in technology
- Partnership for Patients & Hospital Engagement Networks

What did we observe?

- Varied understanding of engagement
- Some efforts focused more on adherence or compliance

What we wanted the framework to convey

- Creating partnerships between all key players
- Engagement happens at multiple levels that influence each other
- Range of engagement opportunities
- Multiple factors support or hinder engagement
- Behavior changes lead to larger culture change
- Whether and how engagement leads to particular outcomes

What are promising efforts?

Examples from the field

Direct Care

- Personal Health Records
- Health coaches
- Mobile apps, On-call nurses to help choose point of care
- Shared decisionmaking, decision aids
- Health literacy -Teach back
- Motivational interviewing
- Public reporting efforts

Examples from the field

Organizational Design & Governance

- Patient and Family Advisors
- Patient and Family Advisory Councils
- Staff and volunteers shadow patients and families to create a flow map of the care experience

Examples from the field

Policy Making

- Public Deliberation
- This Task Force!

How can we use the framework?

Examples of current use

- Assessing efforts of individual organizations and communities
- Addressing specific aspects of engagement (e.g., measurement, technology, research)
- Examining the field as a whole

Organizing framework: Clarify what to do and why

- Inventory efforts to date
- Identify opportunities at all levels
- Use continuum to assess degree of partnership
- Align policies, programs, and funding to engender engagement
- Help to identify ultimate outcomes of engagement

Final thoughts

How can we get there?

- Embrace change
  - Everyone's behavior (that means you too!)
- Better collaboration
- Create supports for change
  - Organizations and systems
  - Alignment of incentives

Not everything has to happen at the same time, or in the same way

All roads lead to where you're going, some just take a little longer.

Let's keep talking

- AIR's Center for Patient and Consumer Engagement http://aircpce.org
- Maureen Maurer, mmaurer@air.org, 919-918-2308

Discussion

- How can the Task Force use this framework?
- What strategies can be encouraged at all levels of the framework?
- How can we push efforts beyond consultation to shared partnership?
- What are existing assets that can be used?
- What incentives need to be implemented / barriers addressed?