



THE ROLE OF ADVOCACY AND ENGAGEMENT TO IMPROVE HEALTH

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Policy Forum**

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AGENDA

Panel -Part 1:

- The Center for Patient Partnerships
- Advocacy and Engagement in the Health Arena
 - Philosophy, Definitions, & Context
 - Applying Advocacy & Engagement

Workshop – Part 2:

- Action planning

CENTER FOR PATIENT PARTNERSHIPS

To Ensure that Patient Experiences Inform Health Care Delivery, Receipt, and Action



PHILOSOPHY: PATIENTS AS KEY TEAM MEMBERS

“In high-functioning health care teams, **patients are members of the team**; not simply objects of the team’s attention; **they are the reason the team exists and the drivers of all that happens.**”

WHAT IS PATIENT ENGAGEMENT?

an **active process** of ensuring that our patients' experience, wisdom and insight are infused into individual care and the design and refinement of our care systems

WHAT IS PATIENT AND HEALTH ADVOCACY?

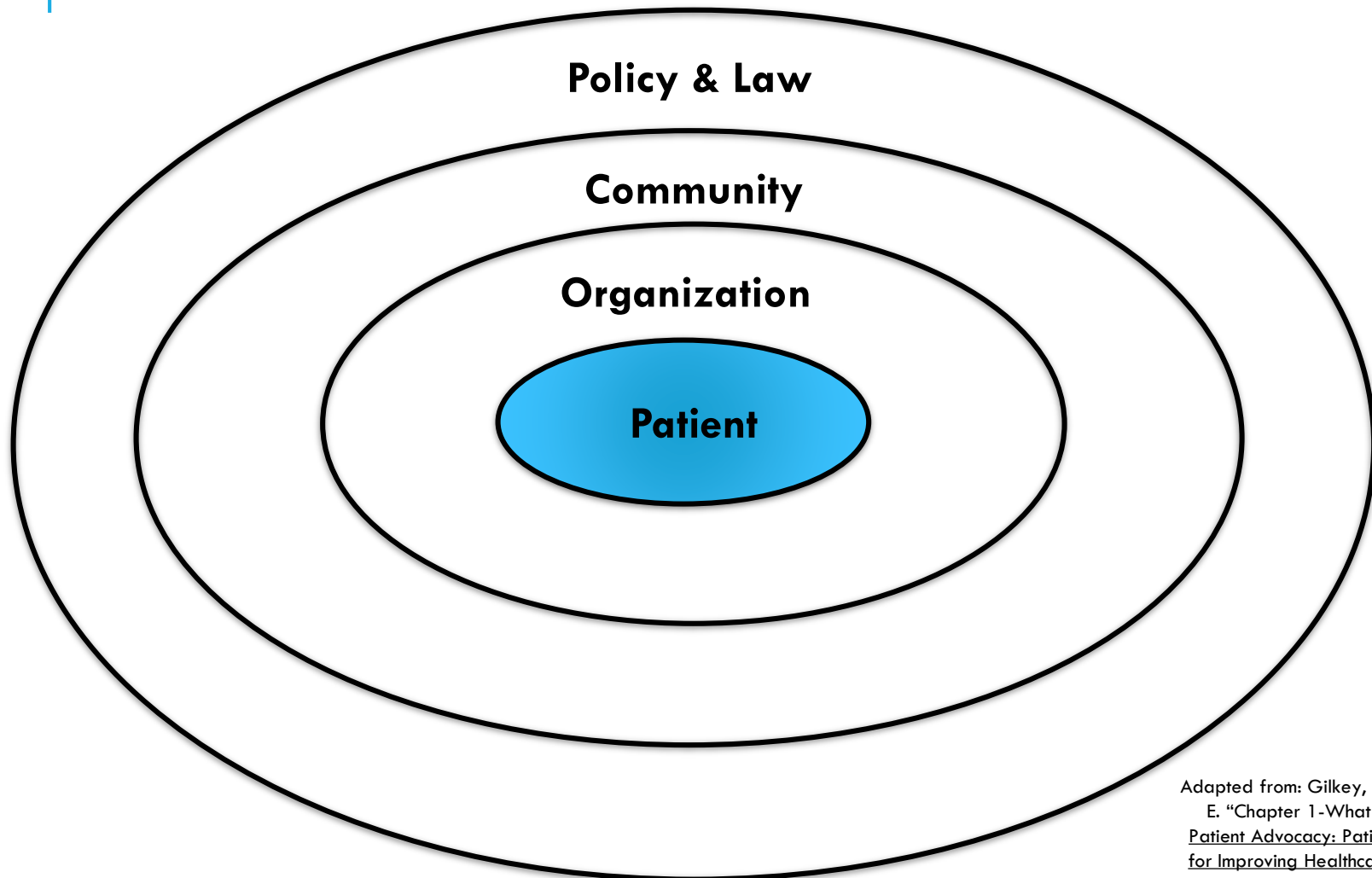
- **Patient Advocacy:** Working on behalf of the interests of a specific patient and empowering that patient to maximize health
- **Health Advocacy:** Advocacy for the social, economic, educational, and political changes that ameliorate suffering and contribute to human well-being

CONTEXT: PATIENT AND FAMILY ENGAGED CARE (PFEC)

Care planned, delivered, managed, and continuously improved in partnership with patients and their families

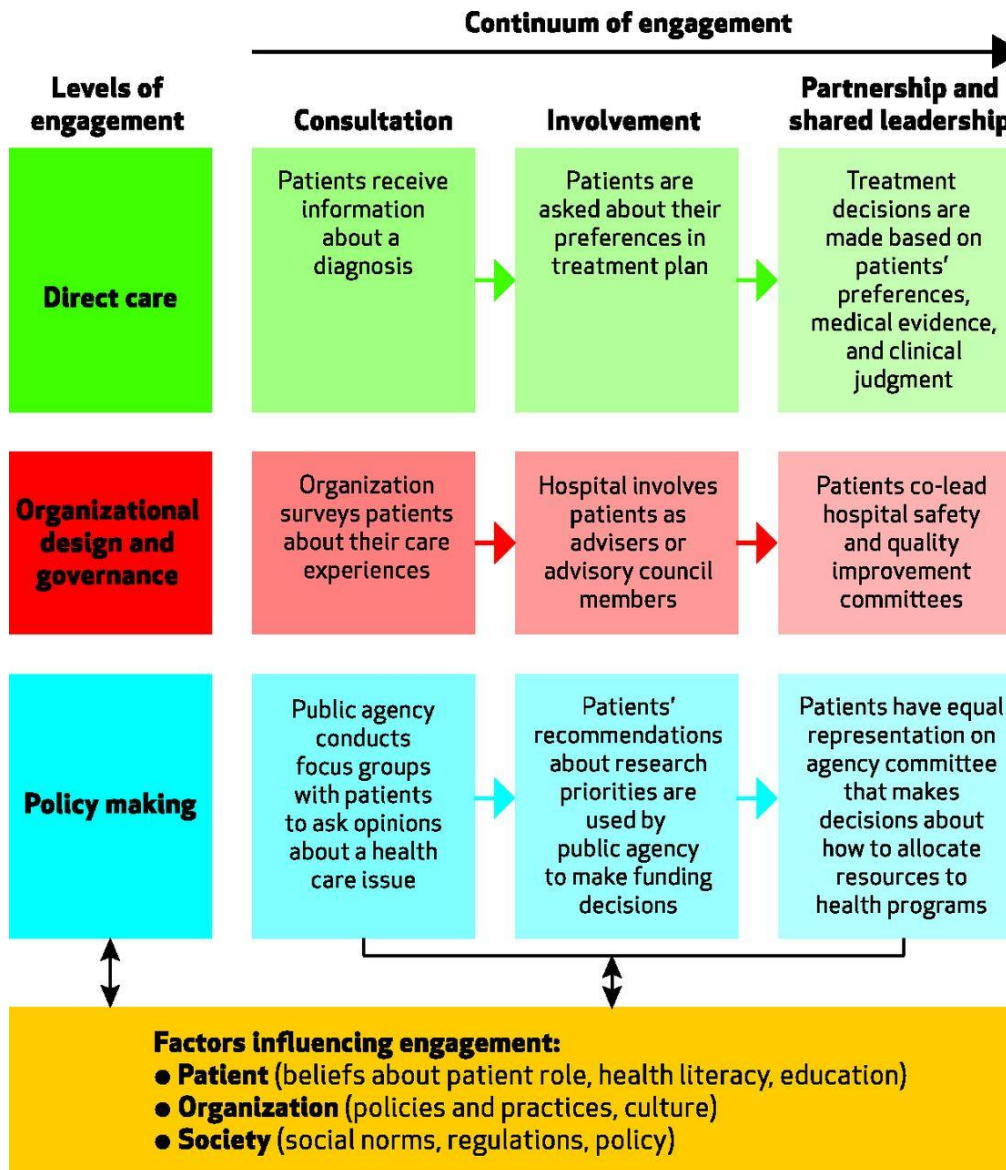
- A shift in the role patients and families
- Broaden focus from care process to organization, systems, and policies
- Patients' experiences and values are honored
- Patients' care experience are incorporated into improvement efforts

ARENAS OF INFLUENCE



Adapted from: Gilkey, M., Earp, J., and French, E. "Chapter 1-What is Patient Advocacy," in Patient Advocacy: Patient Centered Strategies for Improving Healthcare Quality. Edited by J. Earp, E. French, M. Gilkey. Boston: Jones and Bartlett Publishers, Inc. (2008)

A Multidimensional Framework For Patient And Family Engagement In Health And Health Care

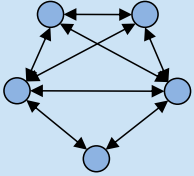
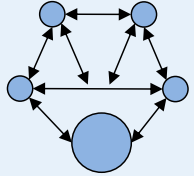
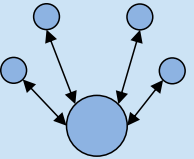
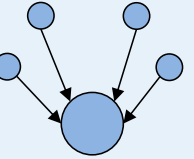
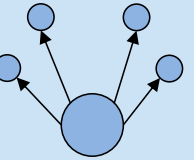


HealthAffairs

K. L. Carman et al. Health Aff 2013;32:223-231

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CATEGORIES OF PATIENT ENGAGEMENT

Engagement Categories		Definition and Methods
PARTNER		<p>Patients are full participants</p> <p><i>Examples: members of a team, governance boards, and improvement initiative work groups.</i></p>
INVOLVE		<p>Patients are advisors</p> <p><i>Examples: ongoing Patient Feedback Panels, Patient Advisory Councils, and non-voting participation in patient safety rounds.</i></p>
DISCUSS		<p>Patients are in dialog with providers and clinic staff</p> <p><i>Examples: focus group or interviews.</i></p>
GATHER		<p>Patients are informers.</p> <p><i>Examples: surveys, cycle time, and suggestion boxes.</i></p>
INFORM/ EDUCATE		<p>Patients are recipients of information and education</p> <p><i>Examples: brochures, health information posters, and electronic health records.</i></p>

- ✧ Continuum
- ✧ All valuable
- ✧ Different methods meet different needs
- ✧ Mix and match
- ✧ Consider each stage of QI

WHY ENGAGE PATIENTS? WHY ADVOCATE?

For improved care

- Shared decision making
- Self-advocacy/Activation

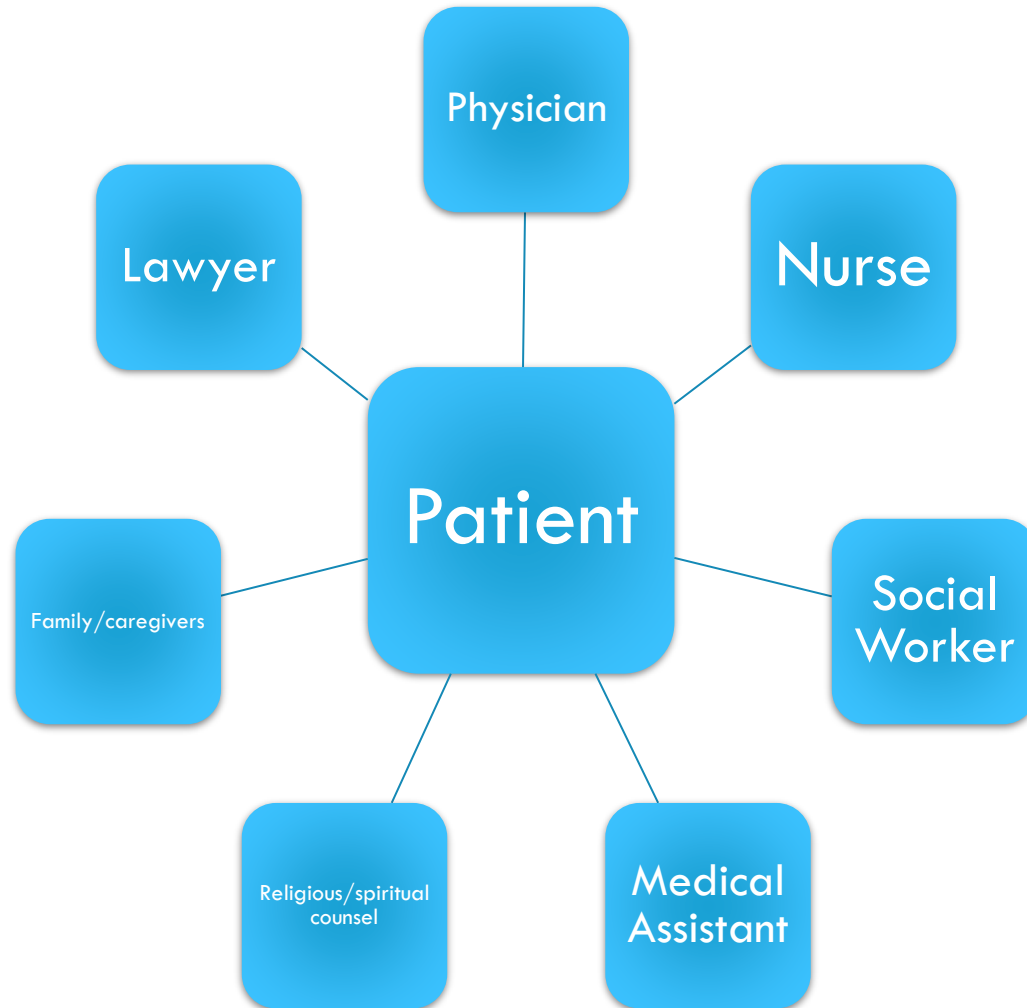
For improved quality

- Reduce low value care

For safety

- Infection control
- Medical errors

ADVOCATE WITH OTHERS; ENGAGE BROADLY



ADVOCACY ROLES

Empathic Listener

Effective Communicator

Counselor

Diagnostician

Conductor (orchestral)

Understanding Identity

Catalyst for Change

Life-long Learner

Capacity Builder

Boundary

Spanner/Interpreter

Transformational Leader

PATIENT ADVOCACY: EMPOWER & PARTNER

Skills:

Listen deeply

Educate; Translate complex info

Empower

Support decision-making

Inform re: rights

Navigate complex systems

Possible Action Plan:

- Hold a patient focus group – ask patients what would help
- Screen patients for “activation” level and teach it
- Implement a shared-decision-making program
- Education campaign about rights and responsibilities

ORGANIZATIONAL ADVOCACY: CHANGE FROM WITHIN

Skills:

Long-term planning

Disruptive self-expression

Verbal jujitsu

Variable-term opportunism

Strategic alliance building

Possible Action Plan:

- Form a patient and family advisory group (PFAC)
- Include a patient on governing boards
- Ask questions of decision-makers: “What would patients think?”
- Change what you can – however small; Change builds on change
- Identify others who share the same goals

COMMUNITY ADVOCACY: COLLABORATE

Skills:

Collaboration

Strategically apply medical & scientific expertise

Identify and help solve problems by contributing your disciplinary perspective

Leadership (appropriately applied)

Possible Action Plan:

- Invite community group leaders to a brainstorming meeting
- Ask other how you can help
- Research evidence-based interventions

POLICY ADVOCACY: CHANGE RULES

Skills:

Effective Communication

Diagnose issues

Leadership

Interpret complex information

Perseverance

Catalyst for Change

Possible Action Plan:

- Join a professional group engaged in legislative advocacy
- Learn about the interests of elected officials
- Research the evidence-base
- Engage in media advocacy – write opinion pieces and letters to the editor, invite journalists to shadow your efforts, appear on the radio

THANK YOU!

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