



Speaker

First Plenary Session

**FINDING THE PATIENT IN HEALTH
RESEARCH & POLICY**



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**What Does “Patient-Centered
Outcomes” Mean?**

Donald L. Patrick, PhD, MSPH

**Finding the Patient in Health Research & Policy
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- **Because every one of you out there in the audience has or will experience disease or disability**
- **Because everyone in their lifetime is likely to need and want health care**
- **Because we all have loved ones and family, friends, colleagues who experience disease, illness, and treatment**

- **“Nothing about us without us”**
- **“See the person, not the illness”**
- **“A beautiful thing happens when we start paying attention to each other. It is by participating more in the patient-provider [sic] relationship that you breathe life into it.”**

- Patient-Centered Outcomes
- Patient-Reported Outcomes
- Patient-Focused Outcomes
- Patient-Based Outcomes
- Patient-Important Outcomes
- Patient Care Outcomes

.....in the context of

- Medical Care, Health Policy, Research
- Patient Focused Drug Development Program
- Patient Participation and Advocacy
- Patients Like Us

Patient-Centered Outcomes

Those outcomes important to patients' survival, function, or feelings as identified or affirmed by patients themselves, or judged to be in patients' best interest by providers and caregivers when patients cannot report for themselves

- **1=Perfect Health 0= Death**
- **Few people believe there are states worse than death, except for permanent coma**
- **Cultural belief in the magic of technology in extending life**

- “The life that I enjoy is being able to do what I want to do”
- Most people highly value independence, ability to do self care, ability to move around the community
- Health care often directed to improving capacity to “be” and “do”



“So remember to look up at the stars and not down at your feet,” “Try to make sense of what you see and wonder about what makes the universe exist. Be curious. And however difficult life may seem, there is always something you can do and succeed at.”

Stephen Hawking



The importance of feelings

- Back pain, headache, feeling miserable with a cold, and depression top reasons for visiting a doctor
- Health is in part subjective and our feelings drive our behaviors and our evaluations

- Research
- Patient Engagement
- Shared decision-making

- <http://www.healthcare.gov/glossary/M/index.html>
- Goal of comparative effectiveness research to compare different medical treatments and interventions to provide evidence on which strategies are most effective in different populations and situations.
- The goal is to empower you and your doctor with additional information to make sound health care decisions



2) FDA Patient Network

<http://www.patientnetwork.fda.gov/>

The best participation and input from patients comes from patients who understand the regulatory framework and processes

Goal:

- Educate patient communities about FDA
- Respond to their questions
- Keep them apprised of opportunities to comment
- Encourage participation in medical product development



IOM Definition of Quality of Medical Care

- *Quality of care* : “The degree to which health services for individuals and populations increase the likelihood of **desired health outcomes** and are consistent with current professional knowledge.”

- “Patient-centeredness” is a dimension of health care quality in its own right, not just because of its connection with other desired aims, like safety and effectiveness.
- Its proper incorporation into new health care designs will involve some radical, unfamiliar, and disruptive shifts in control and power, out of the hands of those who give care and into the hands of those who receive it.

- **Best possible outcomes (above all)**
 - Hope, Not hype
 - Transparency
 - Personal attention
 - Recognition
 - Respect
 - Dignity
 - Choice
- All with “affordable care”



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