Patient Engagement: What Is Needed for Personalized Care Management?

- *Defining Patient Engagement in Research*, **Maya Hanna**, MPH, PhD Candidate, University of Maryland School of Pharmacy

ISPOR and Patient Engagement in Research

**Mission:**
- ISPOR: The leading professional society for health economics and outcomes research (HEOR) globally
- Promote HEOR excellence to improve decision-making for health globally

**Foundational assumptions:**
- Patients should be engaged in HEOR research activities
- HEOR activities should align with legislative requirements and regulatory guidance on patient engagement in research

**Strategic initiative: Patient engagement in HEOR**
- Patient Council, Patient-Representative Roundtables
- Collaboration: Patients and Outcomes Research Experts
- **Patient Centered Special Interest Group**
  - Consensus generated definition for “patient engagement in research”
Getting to a Definition

Define the Gap
- ISPOR Membership Survey
- Targeted scope of literature (databases & gray literature)

Systematic Lit. Review
- Define search strategy
- Abstract Screen (1,767)
- Full-text review (276)
- Extract definitions (239)
- Context of research (9.7%)

Qualitative Analysis
- Develop coding strategy / dictionary
- Coding
- Analysis

Definition Proposal
- Definition developed out of qualitative analysis results
- Multi-stakeholder review
- Final Definition

Patient Engagement in Research

“The active, meaningful and collaborative interaction between patients and researchers across all stages of the research process, where research decision-making is guided by patients’ contributions as partners, recognizing their specific experiences and expertise.”

- ISPOR Patient-Centered SIG
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