


# **PATIENT ENGAGEMENT, PATIENT CENTRIC, WHAT DOES IT ALL MEAN?**



An Open Meeting by the ISPOR Patient Engagement in  
Research Working Group of the Patient Centered Special  
Interest Group

Tuesday, November 1, 2016



# **ISPOR PATIENT ENGAGEMENT IN RESEARCH WORKING GROUP OF THE ISPOR PATIENT CENTERED SPECIAL INTEREST GROUP**

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## Patient Engagement in Research Working Group

### Co-chairs

**François Houÿez**, Director of Treatment Information & Access, Health Policy Advisor EURORDIS  
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### Leadership Group:

**Violeta Astratinei, Biol., Ph.D.**, Melanom Romania, Melanoma Patient Network Europe, Romania

**Laurie Burke, RPh, MPH**, Affiliate Associate Professor, University of Maryland, School of Pharmacy, Maryland, USA

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**Maya Hanna, MPH, Doctoral Student**, University of Maryland School of Pharmacy, Baltimore, USA

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**Francis Nguyen, Student Pharmacist**, University of Maryland School of Pharmacy, Baltimore, USA

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**Amie Scott, MPH**, Business Health Research Analyst, SEAS Capital Partners, Plymouth, MI, USA

**Rainald von Gizycki, MD**, Honorary President, Pro Retina Deutschland e.V., Coordinator, Pro Retina Europe, and Member of Board of Trustees, Pro Retina Foundation Fighting Blindness, Bad Nauheim, Germany

**Russell Wheeler**, Patient Advocate for Leber's Hereditary Optic Neuropathy, Winchester, UK

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## Patient Engagement in Health Outcomes Research: A Snapshot from the ISPOR Community



### Goal

- How to best involve patients and patient representatives in all stages of decision making

### Purpose

- Improving healthcare delivery and outcomes

### Aim

- Define patient engagement
- Recommend a framework for successful engagement of patients, patient representatives, and healthcare consumers within Outcomes research and decision making

### How

- Targeted Literature Review
- ISPOR members survey
- Advocacy for advancing patient engagement in Outcomes research
- Eliciting feedback and involvement from ISPOR membership and stakeholder community

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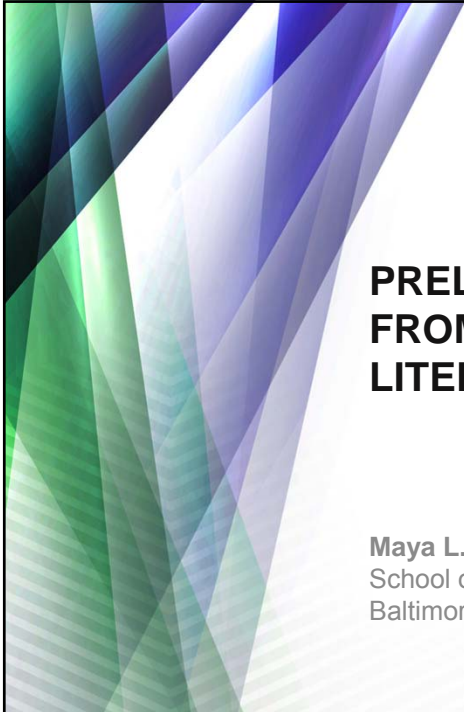
## Patient Engagement in Health Outcomes Research: A Snapshot from the ISPOR Community



### Objectives

- Share results of preliminary work
- Stimulate discussion about patient engagement in Outcomes research among ISPOR membership and other engaged stakeholders
- Encourage patients, patient representatives and researchers to work together to further patient engagement in outcomes research initiatives

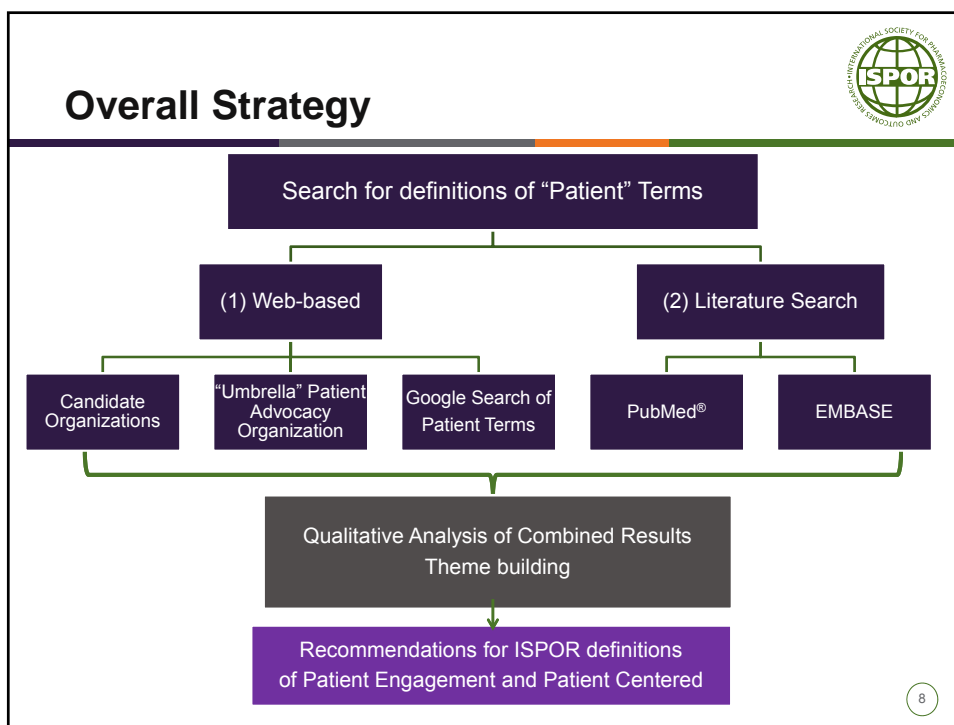
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## PRELIMINARY RESULTS FROM SYSTEMATIC LITERATURE REVIEW

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## Search Strategy – “Patient” Terms Used


- Search terms used

Patient Focused
Patient Focused Drug Development
Patient Focused Outcomes Research
Patient Centered Outcomes Research
Patient Centered/Centric/Centeredness
Consumer Centered/Centric/ Centeredness
Person/People Centered/Centric/Centeredness
Patient Engagement
Consumer Engagement (limit to health care)
Patient Empowerment
Patient Involvement
Consumer Involvement
Patient Input
Patient Oriented
Patient Participation

All terms feed into  
Patient Engagement  
and Patient Centered

\*EU spellings of any terms were also searched. i.e. 'centred'

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## Search Strategy

- (1) Web-based**
  - Presented in ISPOR 18<sup>th</sup> EU Congress (Milan)
- (2) Literature Search:**
  - Literature providing definition on any of the related patient engagement terms
  - From any source but in English
  - Published between 2006 – 2016
    - Phase 1: Abstracts - reviewed for relevance by 2 individuals
    - Phase 2: Full Text – extraction of definitions by 2 individual

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## Literature Search Strategy- Eligibility Criteria

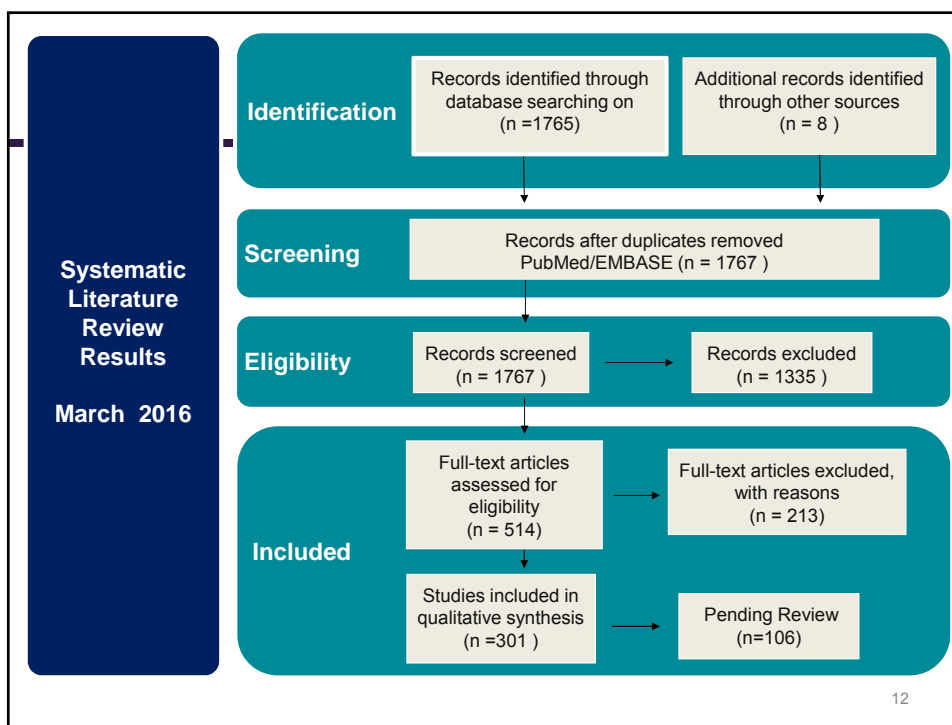
### ■ Inclusion Criteria

- Definition of term is in abstract
- Purpose/Objective of the paper is to define term or introduce, examine, or analyze a conceptual model/framework
- Systematic Review of term definition or concept
- Opinion paper on term about its use or importance in health care/research
- Unclear for inclusion or exclusion without full-text review

### ■ Exclusion Criteria

- No terms defined or framework referenced
- Not health care or research related
- Term used to describe a treatment approach/intervention in a specified population (i.e. colorectal surgery or TBI rehabilitation) without defining term
- Term used in context of improved communications or infrastructure of an organization through information without defining term

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## Data Extraction



- “Patient” term used
- “Patient” term definition
  - *Original, adapted or adopted* from another source
- Source or reference if adapted or adopted
- Context the term/definition used in:
  - Healthcare delivery, research, both, other
- Provision of a framework
- Source or reference of framework

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## Preliminary\* Findings and Results



- 187 Definitions were extracted

Patient Focused (3)
Patient Focused Drug Development (1)
Patient Focused Outcomes Research (2)
Patient Centered Outcomes Research (5)
Patient Centered/Centric/Centeredness (80)
Consumer Centered/Centric/Centeredness (0)
Person/People Centered/Centric/Centeredness (7)
Patient Engagement (28)
Consumer Engagement (limit to health care) (1)
Patient Empowerment (14)
Patient Involvement (20)
Consumer Involvement (0)
Patient Input (1)
Patient Oriented (1)
Patient Participation (24)

**\*\*PLEASE NOTE:** THAT FULL DATA EXTRACTION HAS NOT YET BEEN COMPLETED. THESE DATA ARE PRELIMINARY AND SHOULD NOT YET BE USED OR CITED.

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## Patient Engagement: Keywords from definitions

Includes the following terms:

- Patient Engagement
- Consumer Engagement (limit to health care)
- Patient Empowerment
- Patient Involvement
- Consumer Involvement
- Patient Input
- Patient Participation



## Patient Engagement Themes



### Health Care System / Structure / Delivery

- Incorporating values, experiences, perspectives in design and governance of health care system
- Active influence in the provision of medical care

### Patient / Provider Behavior

- Shared decision making / deliberation / mutual agreement /
- Patients who are information seeking and demonstrating assertiveness
- Clinician respects patients own decision; patients 'voice' is heard
- Patients as expert partners; human capital
- Patient takes control of life and management of disease/health

### Health-related Research

- Identifies gaps in research
- Study recruitment and data collection
- Maximize success and translation of research
- Involved/part of health care policy and quality research



## Patient-centered: Keywords from definitions

Includes the following terms:

- Patient Focused
- Patient Focused Drug Development
- Patient Focused Outcomes Research
- Patient Centered/Centric/Centeredness
- Patient Centered Outcomes Research
- Patient Centered Drug Development
- Consumer Centered/Centric/Centeredness
- Person Centered/Centric/Centeredness
- Patient Oriented



## Patient-centered Themes



### Health Care System / Structure / Delivery

- Involvement in service planning and evaluation
- Care that 'measures up' to patient needs and values
- The right care, to right patient, at right time

### Patient / Provider Behavior

- Clinician respects/responsive to patient needs/preferences/desires/values/goals
- Patients involved in health care planning / therapeutic alliance
- Patient seen as unique human beings/ person rather than disease/ dignity
- Patients as expert partners; human capital

### Health-related Research

- Develop/validate patient-reported outcome assessments
- Endpoints and outcomes meaningful to patients
- End users of benefit-risk framework
- Members of clinical research advisory committee
- Active/relevant community beyond researchers

## Summary



- Caution: This is a preliminary analysis of data abstracted to date
- Multitude of terms identified
- A more limited number of definitions identified
  - A number of themes converging to help us get to standard definitions
  - Some definitions are irrelevant or outdated
- Data abstraction needs to be completed to finalize the qualitative analyses

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## DISCUSSION ON DEFINITIONS AND ATTRIBUTES

**Rob Camp, BS**, Communications Manager,  
European Patients' Academy (EUPATI),  
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## DISCUSSION



- Patient-focused
  - Drug Development, Outcomes Research, other contexts?
- Patient-centered/centric/centredness
  - Drug development, Outcomes Research, other contexts?
- Patient engagement / Consumer engagement
  - limited to health care
  - but what type of health care – individual or sectoral?
- Patient/consumer involvement
  - Taking their pills on time or changing the *involvement cascade*?
  - Patient input, Patient-oriented, patient participation

## Keywords of Patient Engagement and Centeredness: Head to Head




### PATIENT ENGAGEMENT



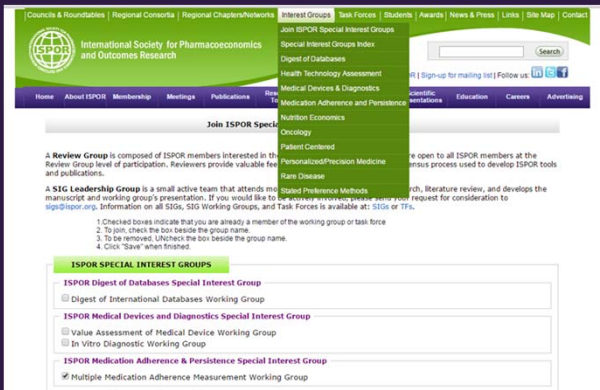
### PATIENT-CENTERED



## Sign up as Review Group Member



- Sign up as Review Group Member
- Join ISPOR Special Interest Groups
- Need ISPOR membership number
- Business card to Theresa or Clarissa



## Patient involvement?



- Communicate information from the broader Community to the study - design, accrual, participants' rights and responsibilities, etc.
- The research question addresses a health issue that is important and relevant to the community.
- There is sense of partnership with the study team.
- The Team answers all questions and/or doubts of the patient group, including potential risk/benefit to participants.
  - Innovation and transparency
- Cooperation
- Ongoing communication
- Regular meetings/Updates
- to provide feedback on the trial protocol, the informed consent document, and any educational materials to be used in the community

## Patients + Team interaction



- Team (PI, study team, staff, etc)
  - Design, process, ethics, feedback, results
- Other community
  - Design, accrual, rights, responsibilities, questions, concerns, expectations, quality of life, timeliness
- Do we need to do all this?
- If we don't, someone will do it for us (private advisory companies, “patient advocacy” companies, etc)