Enabling ISPOR Member and Patient Advocacy Group Research Collaboration: A Volunteer Plan

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F7: Tuesday, May 22, 2018, 6:15-7:15
ISPOR 2018 - Baltimore MD

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Enabling ISPOR Member - Patient Advocacy Group Research Collaboration

Objectives

- Enable pro bono research analytic support for resource-constrained patient groups
    - Research design, survey research, data analysis
    - By students, or experienced members interested in volunteer work
- Provide an engagement opportunity with patient groups for ISPOR member research

Rationale

- Mechanisms to link patient groups and researchers are not yet fully developed
- On both the patient and researcher sides, pre-contact information about prospective partners could improve both their confidence in engaging and the "efficiency" of that engagement.
- ISPOR, in collaboration with the National Health Council, is well-placed to help patients and researchers find suitable "matches" for their research needs

2

Moderator	**Richard J. Willke, PhD,** Chief Science Officer, ISPOR, Lawrenceville, NJ, USA
Speakers	**Jason Harris, BA,** Associate Director of Policy and Programs, National Health Council, Washington, DC, USA
	Brian Ung, PharmD, MS, Post-Doctoral Fellow, US Health Economics and Outcomes Research, Celgene Corporation, Summit, NJ, USA
	Laura T. Pizzi, PharmD, MPH, Professor and Director, Center for Health Outcomes Policy and Economics, Rutgers University, Piscataway, NJ, USA

Other working group members
- **Eleanor Perfetto, PhD, MS,** NHC
- **Zeba Khan, PhD**, Celgene
- **Debbie Zeldow, MBA,** National Bone Health Alliance

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Patient Community Engagement in Value Assessment A Matchmaking Program
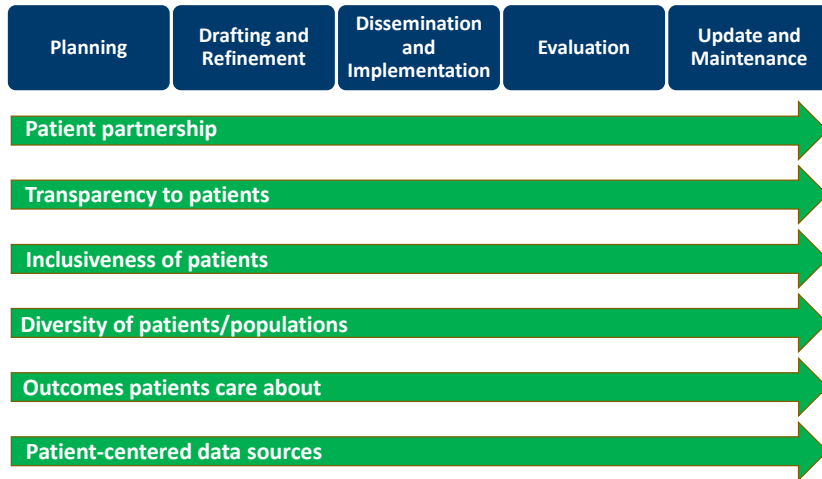
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NHC Value Initiative

- *NHC Patient-Centered Value Model Rubric*
- NHC Value Framework Get-Ready Check List
- Qualitative research on how Health Technology Assessment groups world wide engage patients
- Qualitative research on how patients define and describe "value"
- *NHC Value Workgroup*
- Tackling Representativeness: A Roadmap & Rubric
- Health Economics & Value Assessment Education
- Publications

Domains of Patient Centeredness and Engagement

Planning	Drafting and Refinement	Dissemination and Implementation	Evaluation	Update and Maintenance

Patient partnership →

Transparency to patients →

Inclusiveness of patients →

Diversity of patients/populations →

Outcomes patients care about →

Patient-centered data sources →

7

Value Model Rubric: Example

	Characteristics of Meaningful Patient Engagement in Model Development	Other Characteristics of Patient-Centeredness in Model Development
Patient Partnership	Patients are recognized as partners and are integrated in all aspects of model development phases	Patients are engaged in pilot testing and refinement of the model
Transparency	The process for selection of patient representatives is transparent	The methodology is made transparent to patients in a timely manner
Inclusiveness	The patient community is involved throughout the process	The draft model is vetted with a broad coalition of stakeholders, including patients

8

NHC Value Workgroup

- 2016 – Formed
- Patient Advocacy Organizations engaged and/or interested in value assessment
- Monthly standing calls, information sharing
- Developed more formal work products, including publications and proposals

So… What's next?

NHC-ISPOR Matchmaking Pilot

- Enhance patient community engagement in value assessment

- Build positive relationships between the patient and research community

10

5

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Patient Advocacy Group (PAG) Interview

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Patient Advocacy Group (PAG) Interview

Objectives

- Understand the health economics and outcomes research (HEOR) needs of PAGs
- Understand the level of knowledge of key HEOR terms
- Explore the expectations and perceptions of HEOR
- Identify the level of resources available to conduct HEOR
- Document past experiences with HEOR

12

Interview Questions

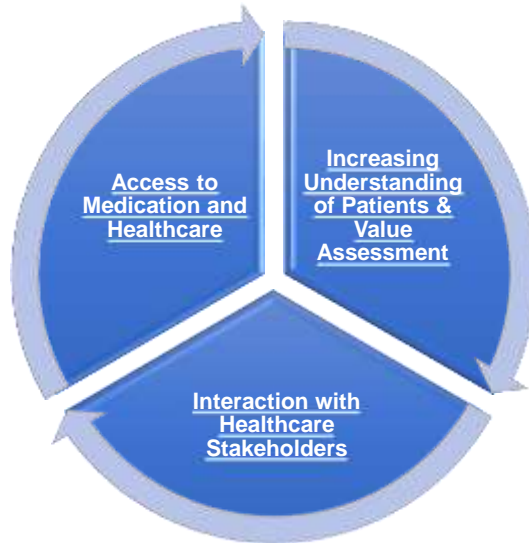| PAG Characteristics	Does your organization keep track of membership numbers?
Awareness of Key Terms	How would you describe: (1) Health economics (2) Outcomes research (3) Value, as it pertains to healthcare
Research Priorities and Expectations	How do you expect your organization to benefit from health economics & outcomes research activities?
Research Resources	Do you have research data (i.e. patient surveys, registry) available within your organization?
Research Experience	Does your organization have research priorities and/or plans to conduct health economics and outcomes research in the future? Please describe the most recent research project your organization has been a part of.

Demographics & Research

Interviewee Demographics

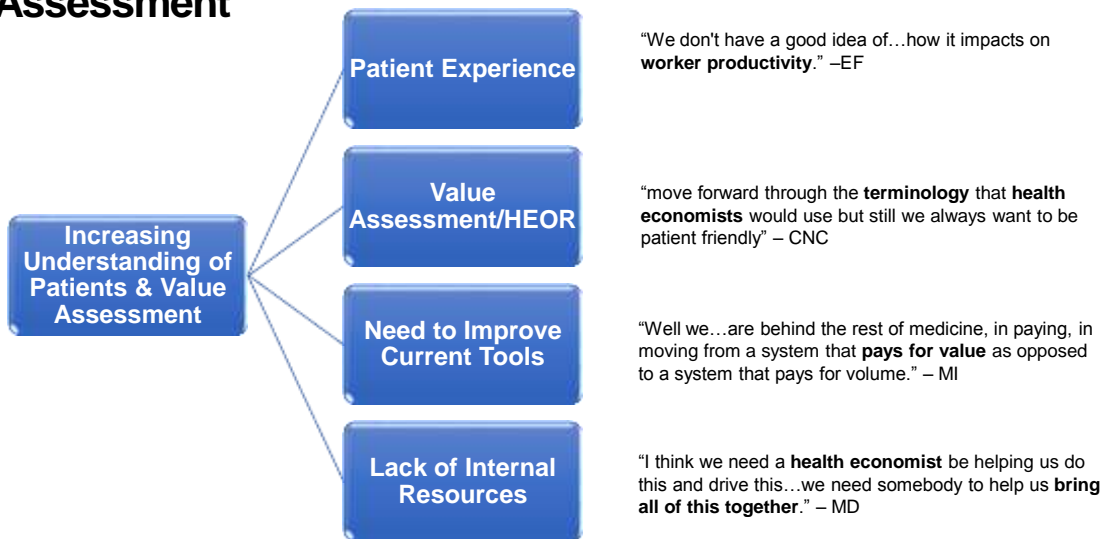|	Interviewees (%) (n=13)
Gender	
Male	4 (31)
Female	9 (69)
Highest Education	
Bachelor's degree	1 (8)
Master's degree	8 (61)
PhD	1 (8)
JD	3 (23)
Level Within Organization	
Analyst	1 (8)
Director	5 (38)
Vice President/President	6 (46)
C-Suite	1 (8)

Usable data

Lack of HEOR staff

ICER

Patient Advocacy Group (PAG) Interview Themes

Increasing Understanding of Patients & Value Assessment

Increasing Understanding of Patients & Value Assessment

Patient Experience

"We don't have a good idea of…how it impacts on **worker productivity**." –EF

Value Assessment/HEOR

"move forward through the **terminology** that **health economists** would use but still we always want to be patient friendly" – CNC

Need to Improve Current Tools

"Well we…are behind the rest of medicine, in paying, in moving from a system that **pays for value** as opposed to a system that pays for volume." – MI

Lack of Internal Resources

"I think we need a **health economist** be helping us do this and drive this…we need somebody to help us **bring all of this together**." – MD

Interaction with Healthcare Stakeholders

"we've received **limited government funding, government grants, PCORI**" – PF

"We have been working with other **clinicians…**on some **definitions around outcomes**" – MD

"the recent **ICER review…**we would be much more effective on behalf of on the part of our population that we serve, you know, if we had **immediate access to people…**with a certain amount of **technical expertise**." –AF

"And what we saw happen was that some **payers** were creating their own outcomes for **enabling access**" –MD

Interaction with Healthcare Stakeholders

Research Partners

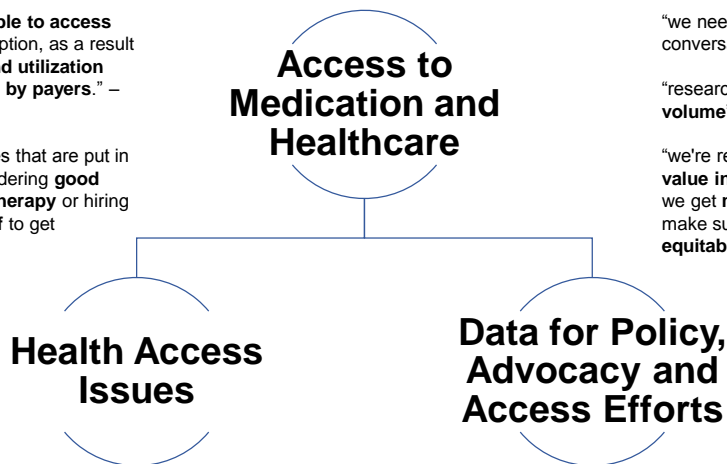Value Assessment & Payers
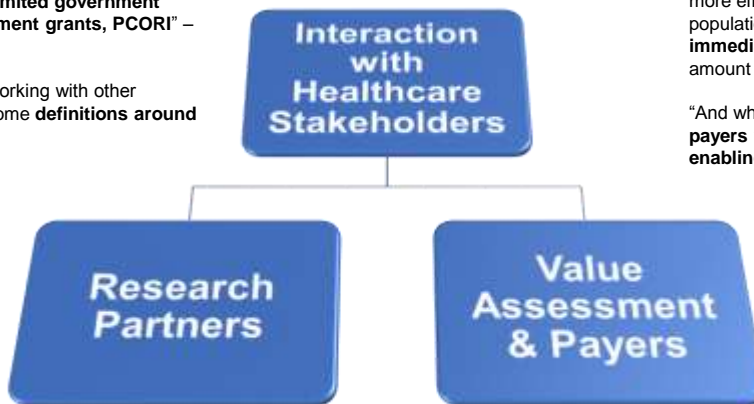
Access to Medication and Healthcare

"Many people…are **unable to access** their preferred therapy option, as a result **of insurance design and utilization management practices by payers**." – PF

"all the different obstacles that are put in **delay** of a physician rendering **good care**, whether it's **step therapy** or hiring that person on their **staff** to get **preapproval**." –HA
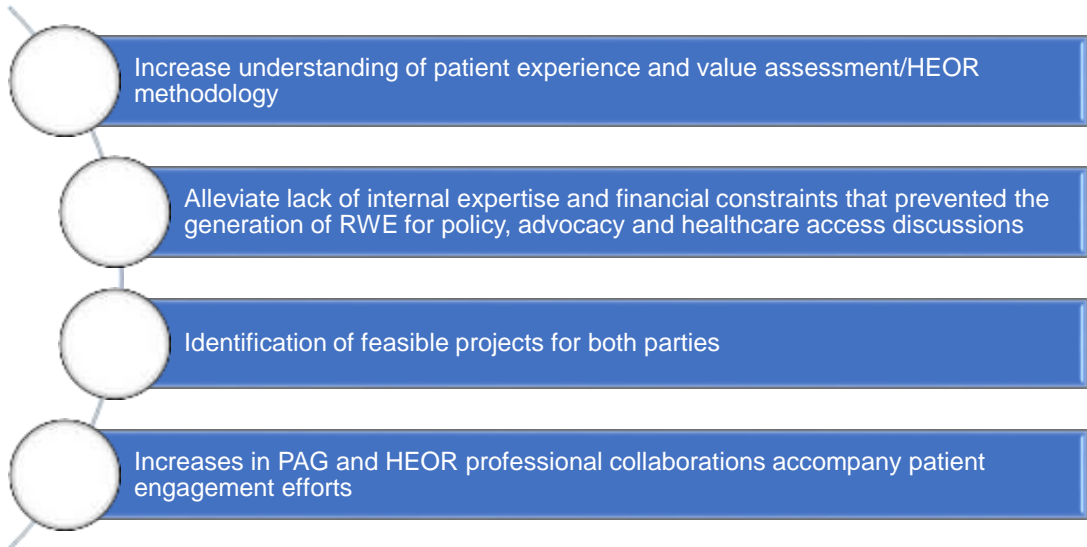
"we need these need to be **data driven** conversations from our perspective" –MD

"research that could drive **value over volume**" –MI

"we're realizing that this whole idea that **value in healthcare**, is going to demand that we get **more and more into this order** to make sure that health policies are **fair and equitable.**" –ID

Access to Medication and Healthcare

Health Access Issues

Data for Policy, Advocacy and Access Efforts

Summary

- Increase understanding of patient experience and value assessment/HEOR methodology

- Alleviate lack of internal expertise and financial constraints that prevented the generation of RWE for policy, advocacy and healthcare access discussions

- Identification of feasible projects for both parties

- Increases in PAG and HEOR professional collaborations accompany patient engagement efforts

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ISPOR Member Survey and Proposed Process

Laura T. Pizzi, PharmD, MPH
Professor and Director
Center for Health Outcomes, Policy, and Economics
Rutgers University

ISPOR Member Survey: Results

- **240 responses collected between November 2017-January 2018**

  - Major employment sectors represented were the life sciences industry (22.9%), academic faculty/staff (19.6%), students (16.7%), and consulting / contract research (16.3%)
  - Most respondents had ≥5 years' experience in HEOR (62.9%)
  - Nearly half had prior experience working with a PAG (46.7%)

- **88.8% of respondents indicated interest in working with a PAG as a volunteer HEOR researcher**

  - Most were "very interested" (50.8%) or "moderately interested" (37.9%)
  - Most were interested in small projects (64.8%) and were able to engage within the next 2 months (43.7%) or 2-6 months (39.0%)
  - Among respondents interested in working in a specific disease area, oncology was the most common (41.4%)
  - Those with fewer years of experience in HEOR were more interested in working with a PAG (p=0.008)

Proposed Matching Process

1. ISPOR and NHC review interested members

   - Responsible individual at each organization will screen those interested
   - Project topic and scope considered at this stage
   - Committee with joint representation from ISPOR and NHC will review and approve them

2. Proposed match is presented to each party

   - If both agree, communication will be arranged
   - If both agree after this communication, the relationship will be formally initiated

22

Proposed Matching Process, continued

- After the match:
  - 3 month progress report requested by ISPOR/NHC to refine the program
  - Subsequent progress reports would also be useful, but are voluntary
  - Matched parties asked to share publications or non-proprietary reports resulting from the work
- Match can be continued or terminated as determined by the parties

23

Next Steps

- Refine the matching process, responsibilities of each party, and evaluation approach
- Generate ongoing interest via websites, newsletters, and conference presentations
- Initiate pilots (approximately 2)
  - National Headache Foundation (NHF)
  - Familial Hypercholesterolemia (FH) Foundation

24

Group Discussion

- Invited comments from PAG representatives
- Open comments from ISPOR members

Before leaving, please complete participant interest form and bring it to the front of the room

25

Supplemental Slides

26

Patient advocacy group responsibilities

- Specify the work that is needed, what its purpose is, and when it is needed. A template will be used for this purpose to help the patient group communicate its needs. It will be used to facilitate communications with the researcher so the patient group and researcher can agree on feasible objectives for the work
- If ethical (IRB) review is required, cooperate with the researcher to obtain it
- Provide a contact person group who is the accessible point-person for researcher communications
- Indicate what resources (e.g., data sources) are available that would be useful in the work and how they may be made available to the researcher (included in the template format)
- Provide ongoing collaboration with the researcher
- Be transparent with the researcher as to how the work is to be used and communicated
- Publicly acknowledge the research collaboration as appropriate with the researcher's approval (e.g., acknowledgment on website, co-authorship on reports and documents)

27

ISPOR researcher responsibilities

- Review the work needed and provide an objective review of what can or cannot be done, in what depth, and in what time frame; after discussion with the group, agree on feasible objectives for the work.
- If ethical (IRB) review is required, cooperate with the group to obtain it.
- Maintain confidentiality about the work to the degree desired by the group, including signing a non-disclosure agreement if appropriate.
- Be accessible for group inquiries.
- Do not share any resources provided by the group unless sharing is agreed to in advance; sign and abide to terms of a data-sharing agreement if needed.
- Collaborate with the group to provide interim work products as appropriate, and regularly check progress against timelines.
- Obtain the group's permission before submitting any work for presentation or publication, and acknowledge the group's support as appropriate; update the group on the results of any submissions.

28

ISPOR/NHC responsibilities

- Provide general oversight for the program via a joint committee of ISPOR and NHC staff and/or members.
- Communicate general program parameters, guidelines, status, and activities (e.g., ISPOR Forums) to interested parties.
- Receive and evaluate requests from interested parties, identify and propose matches, participate in opening call(s) between parties, help clarify objectives of work.
- Provide an ongoing ISPOR/NHC contact for each match.
- Assist in resolving any issues that may arise.
- Manage participant expectations.

29