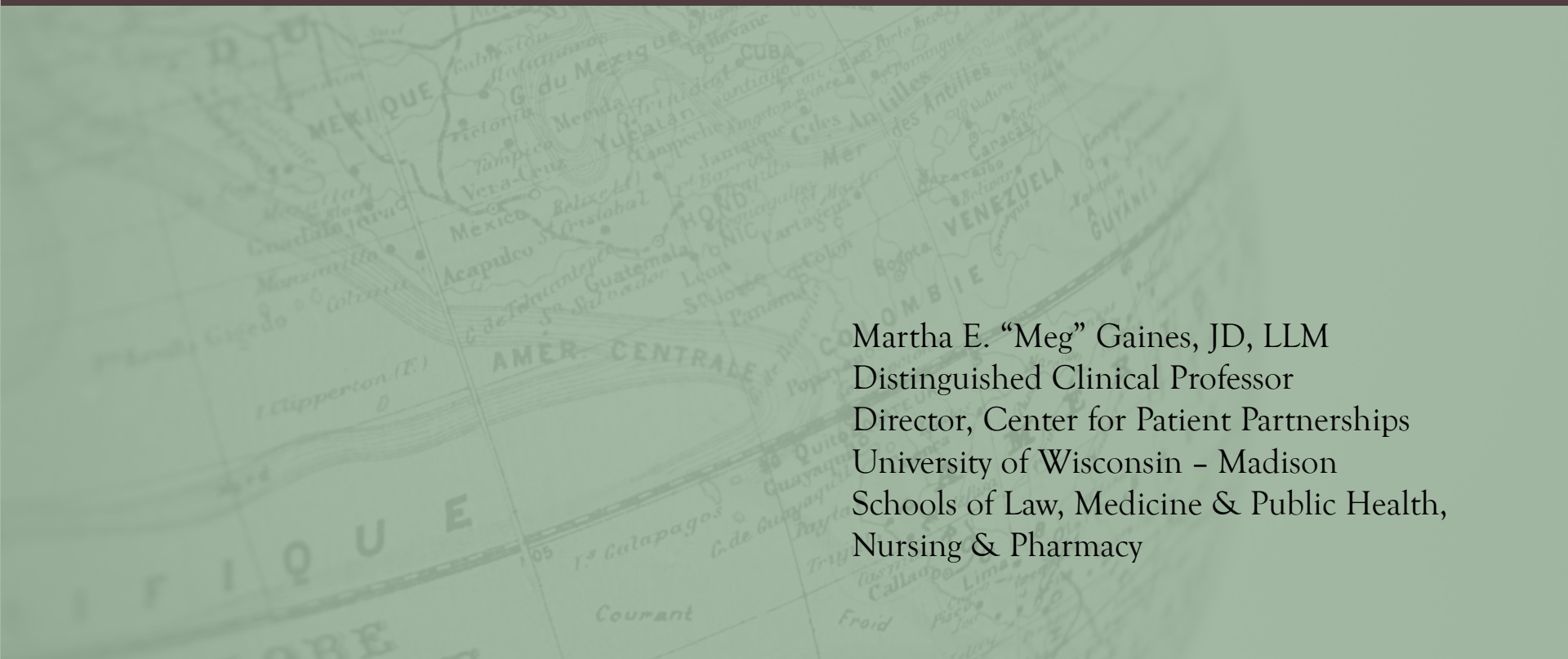


# Partnerships, Patients & Research, OH MY!:

The Why, What, When, Who and How of Engaging Patients in Research



Martha E. “Meg” Gaines, JD, LLM  
Distinguished Clinical Professor  
Director, Center for Patient Partnerships  
University of Wisconsin – Madison  
Schools of Law, Medicine & Public Health,  
Nursing & Pharmacy

# CPP & ME

- A funny thing happened on the way to my 40s...
- Alchemy: The Center for Patient Partnerships
- Our wheel house: The Patient Voice.
  - Advocacy + Transdisciplinary Education
  - Organization redesign
  - National initiatives
- I am a patient partner in research.
  - NCRA, DOD Grant, surgery decisional tool, HAI control.

# PCORI: A NEW WIND BLOWING

- New funding opportunity
- But, engaging patients is foreign, complex and time consuming.
- Already in Phase 2, after Phase 1 failures.
- How can we maximize the possibility of successful collaboration?
- Why, what, when, who & how can we engage patients effectively?

# WHY ENGAGE PATIENTS IN RESEARCH?

- Because it is essential to success.
- Increases:
  - ✓ Accuracy
  - ✓ Relevance
  - ✓ Representativeness
  - ✓ Effectiveness
  - ✓ Implementation
  - ✓ Dissemination





# WHAT CAN PATIENTS OFFER TO RESEARCH?

- Accurate definition of the problem.
- Identify relevant data.
- Suggest data collection methods, locations & populations.
- Help collect data.
- Offer diverse perspectives in data analysis and interpretation.
- Co-conceive and pilot interventions, interpret results.
- Help refine interventions.
- Suggest implementation strategies.
- Support publicity for implementation and dissemination.

# PATIENT ROLES – PCOR/CER

**Figure.** Enhancement of Comparative Effectiveness Research (CER)  
Through Continuous Patient Engagement

Step in CER Process	Purpose of Patient Engagement
Topic solicitation	<ul style="list-style-type: none"><li>■ Identify topics that are important to patients, caregivers, and the community</li><li>■ Propose topics to be investigated</li></ul>
Prioritization	<ul style="list-style-type: none"><li>■ Solicit feedback on relevance and priority of topics</li><li>■ Discuss the urgency of addressing topics</li></ul>
Framing the question	<ul style="list-style-type: none"><li>■ Ascertain questions' relevance and usefulness</li><li>■ Assess "real-world" applicability</li></ul>
Selection of comparators and outcomes	<ul style="list-style-type: none"><li>■ Identify comparator treatments of interest</li><li>■ Identify outcomes of interest</li><li>■ Incorporate other aspects of treatment</li></ul>
Creation of conceptual framework	<ul style="list-style-type: none"><li>■ Provide a "reality check"</li><li>■ Verify logic of conceptual framework</li><li>■ Supplement with additional factors not documented in the literature</li></ul>
Analysis plan	<ul style="list-style-type: none"><li>■ Verify importance of factors and variables</li><li>■ Ascertain whether there is a good proxy for a specific concept</li><li>■ Inquire about potential confounding factors</li></ul>
Data collection	<ul style="list-style-type: none"><li>■ Determine best approaches for data collection (eg, trial, registry, medical charts)</li><li>■ Assist with selection of data sources</li></ul>
Reviewing and interpreting results	<ul style="list-style-type: none"><li>■ Assess believability of results</li><li>■ Suggest alternative explanations or approaches</li><li>■ Provide input for sensitivity analysis</li></ul>
Translation	<ul style="list-style-type: none"><li>■ Interpret results to be meaningful</li><li>■ Document which results are easy or difficult to understand</li><li>■ Indicate which results are counterintuitive</li></ul>
Dissemination	<ul style="list-style-type: none"><li>■ Facilitate engagement of other patients</li><li>■ Help other patients to understand findings</li></ul>

# WHEN SHOULD PATIENTS BE ENGAGED?

- From the start and all the way through.
- Naming the right problem → (the lateness problem).
- Getting the right data → (QoL survey revamp, mosquitos...)
- Data collection → (AAB online goldmine)
- Data interpretation → (why would they say that?)
- Designing the intervention → (have you washed your hands?)
- Testing the intervention → (mosquito netting vs. plug it in)
- Implementation → (the new clinic map snafu)
- Dissemination → (AAB newsletter)

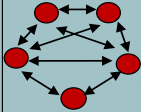
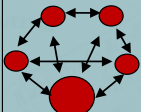
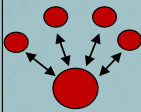
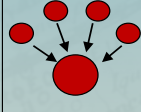
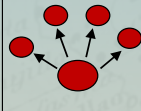
# WHO SHOULD BE ENGAGED?

- The "typical patient" fantasy
- The representation trap
- Safety in numbers for patients & researchers
- Those who are “interested” and “emotionally involved” in the research question (Mullins)
- And, it depends on the task...



# MATCH PATIENTS & LEVELS TO TASKS

- Continuum, early & often!
- Mix and match levels to meet different needs
- Different patients enjoy different levels
- The higher the level
  - Richer, deeper data
  - More varied input
  - More preparation required
  - More transformational

Engagement Levels		Definition and Methods
PARTNER	5 	<b>Patients are full participants</b> <i>Engaged as full research team members from the start</i>
INVOLVE	4 	<b>Patients are ongoing advisors</b> <i>Engaged in a regular manner, when needed, over the course of the project</i>
DISCUSS	3 	<b>Patients provide input and receive feedback</b> <i>One-time focus groups or interactive interviews</i>
GATHER	2 	<b>Patients are informers</b> <i>Surveys, cycle time, suggestion boxes</i>
INFORM/ EDUCATE	1 	<b>Patients are recipients of information and education</b> <i>Websites, social media, newsletters</i>

# HOW TO ENGAGE PATIENTS?

- Invite:
  - Intentional invitation
  - Value time, compensation matters
  - Support for research vs. desire for individualized care
  - Think of the little things
- Welcome
  - Whole staff ready, convinced, committed
  - New ways of being together
- Agree
  - A meeting of the minds
  - Job description – discuss, agree, finalize and adjust as you go
  - Patients who understand their roles are more effective (Mullins)

# PCORI MEANINGFUL ENGAGEMENT

## What Does Meaningful Engagement Mean?



# PCORI: PATIENT ENGAGEMENT DEFINED

- “...(T)he *meaningful involvement* of patients, caregivers, clinicians and other healthcare stakeholders *throughout the research process* – from topic selection through design and conduct of research to dissemination of results...”
- What does meaningful involvement mean to you?



# PCOR PRINCIPLES

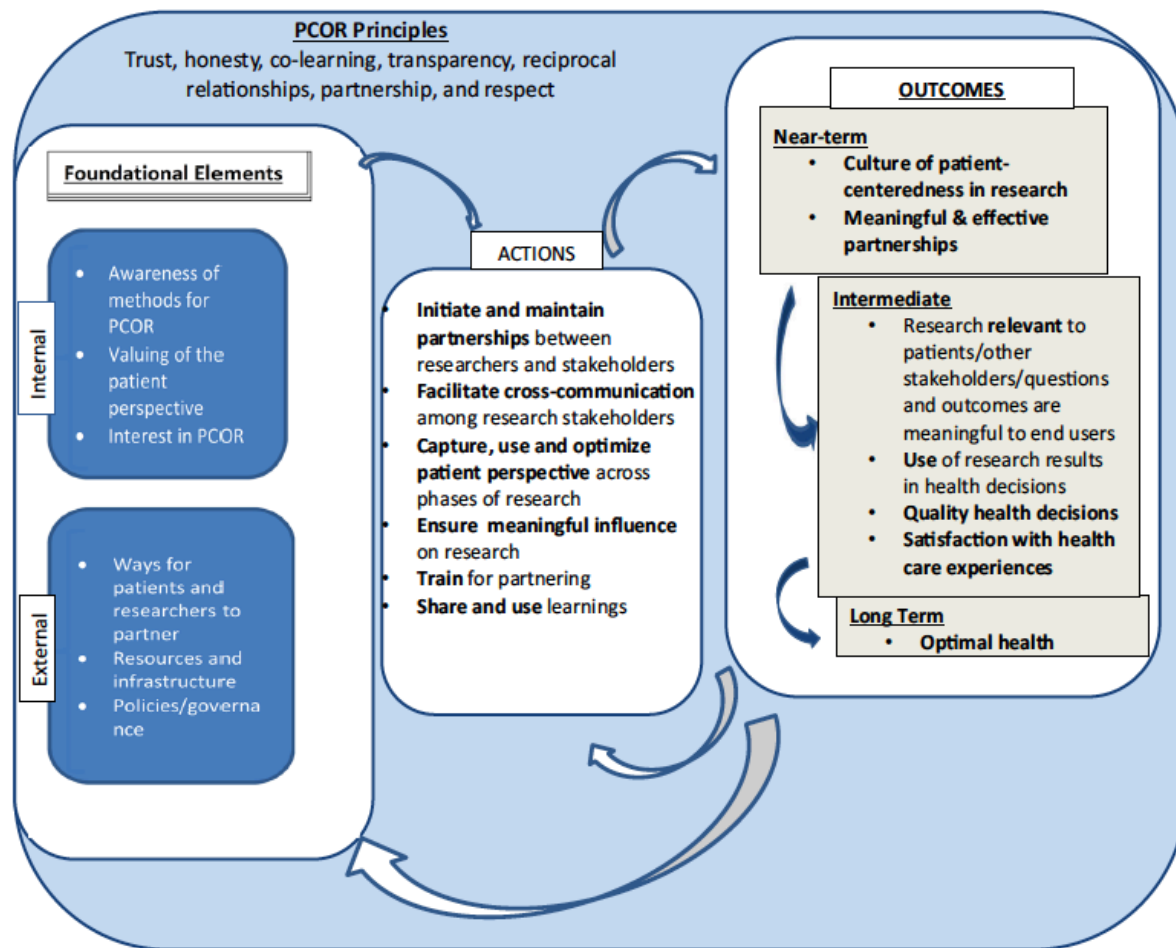


Fig 1 Conceptual model of patient-centered outcomes research

# LOIS AND HER TEAM



# CO-CREATED MATERIALS

- Toolkits
  - Coach version
  - Team version
- Patient Welcome Packet Template
- Additional Patient QI Booklet
- Guide to Internal Resources & Policies



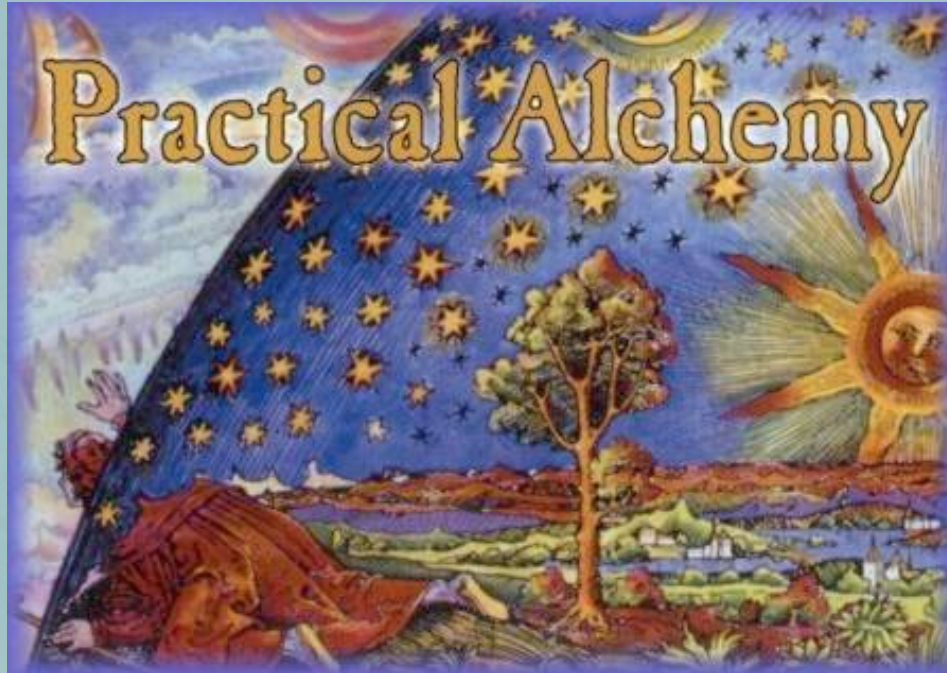
Toolkit at: <http://hipxchange.org/PatientEngagement>

# PUBLICATIONS AND RESOURCES

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- Mullins, C. D., et al, “Continuous Patient Engagement in Comparative Effectiveness Research,” JAMA, April 18, 2012 – Vol 307, No. 15.
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# ALCHEMY: NOUN



“...A seemingly magical process of transformation, creation, or combination...”