

Patient Engagement Studio

Involving Patients in Health
Research and Innovation

Presentation to Great Plains IDeA-CTR

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Researcher

Peggy Wagner

Patient Experts

Mary McCarthy

Johnny Payne

Hiram Springle

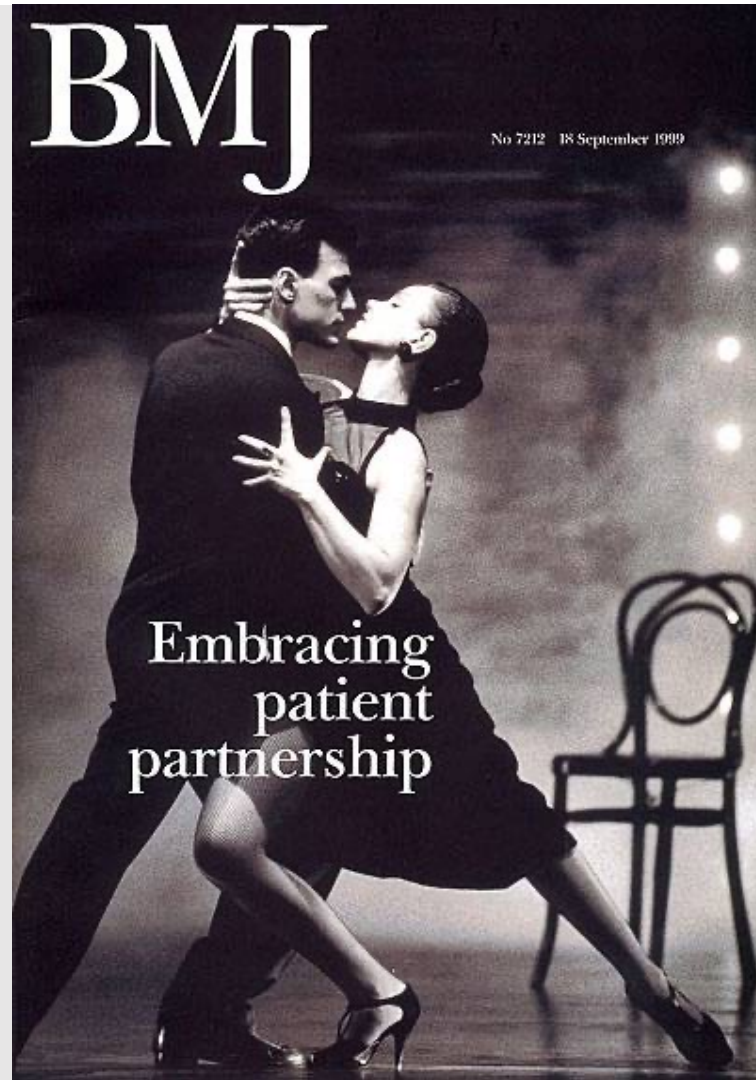
Jessica Sterling

We live in the Era of the Patient

- Patient-centered care
 - Person-centered care
 - Patient- and family-centered care
 - Patient-centered medical home
-
- Patient activation
 - Motivational interviewing
 - Shared Decision making
-
- Patient engagement Health IT
 - Consumer engagement
 - Consumerism/Segmentation
-
- Patient experience of care—Triple Aim, Quadruple Aim
 - Patient-centered outcomes research institute (PCORI)

PATIENT- CENTERED CARE 1999

23 Years later



What is and why have a Patient Engagement Studio?

01

To add patient and community stakeholder perspective to research

02

Include patients as patient “scientists” or “experts”

03

Strengthen the quality and relevance of our research in order to subsequently improve the patient experience of care

Relationship of patient questions and research questions

1

Think about the
questions that
patients have . . .

2

Those questions
are essentially the
same as research
questions . . .

3

Just with different
language.

Patients have questions about the Mysteries of Health

01

What has
happened to me?
(Diagnosis)

02

Why did this
happen?
(Etiology)

03

What is going to
happen to me?
(Prognosis)

Patients have questions about the Medical World

01

What are you
(they) going to do
to me?
(Treatment)

Why are you going
to do that?
(Evidence)

Will it hurt?
(Pain)

What are the
benefits and harms
associated with tx?
(PCORI)

Patients have questions about the Future

01

When and how
will you know
what this means?

When and how
will I know what
this means?

What can the
health care system
do to improve my
outcomes?

What can I do to
improve my
outcomes?

How will I pay for
this?

Benefits of Patient Perspectives in Research

- **Benefits**

- Establishing credibility
- Anticipating controversy
- Ensuring transparency and accountability
- Improving relevance
- Enhancing quality
- Increasing dissemination and uptake of findings



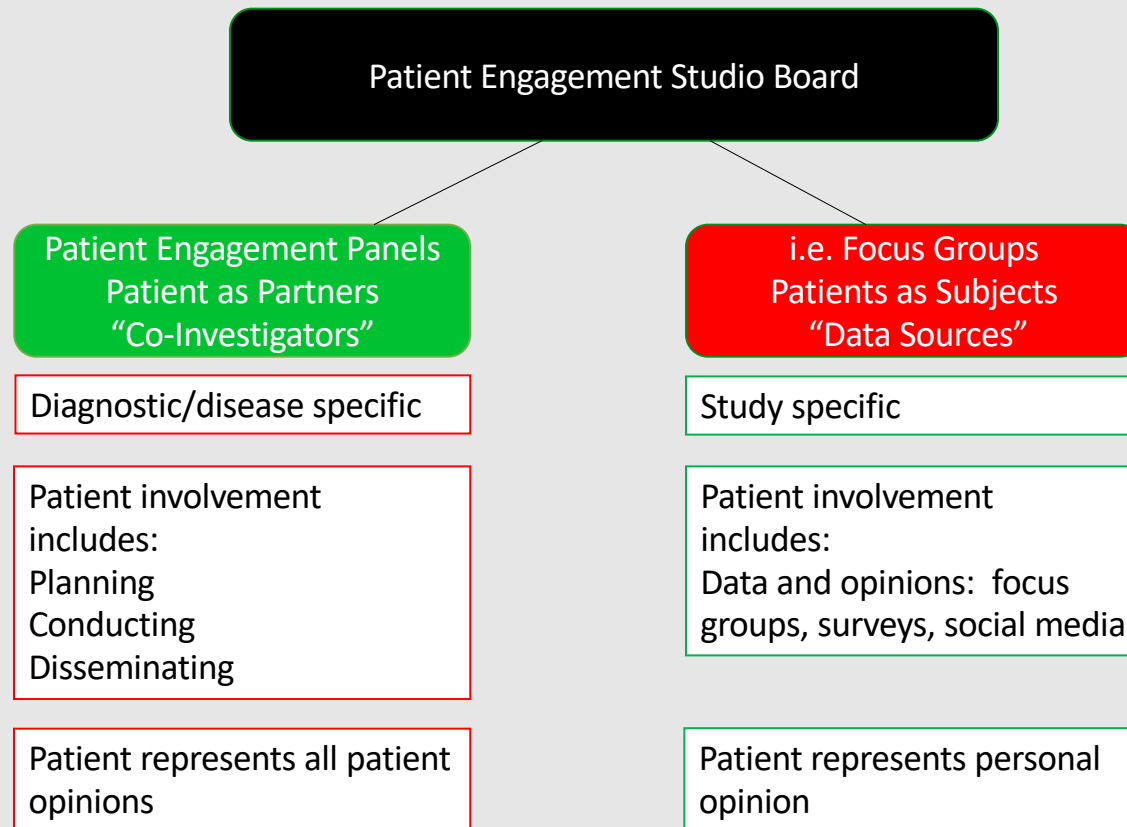
Two ways we operationalized this . . .

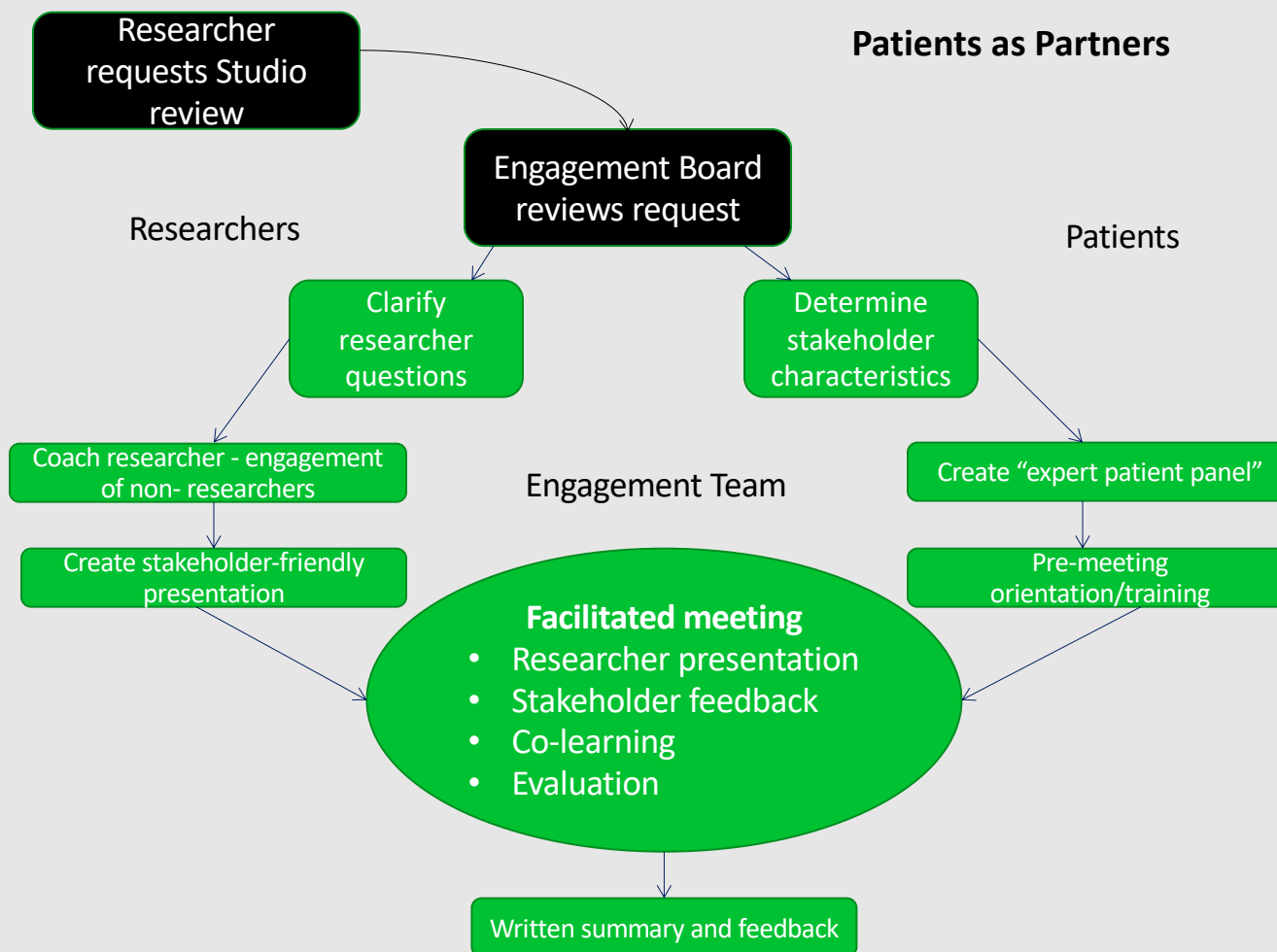
- Researcher requests
- Patient-generated ideas

Overarching Studio Board Membership

- 6 permanent patient members
- Research panel members: Chair, 3 rotating
- Clinical representatives: 3 rotating
- Support and Connection: Patient experience of care representative, Staff Associate

Differentiating Patients as Partners vs Patients as Data Sources





Based on model of Joosten et al, Academic Medicine, 2015.

Planning the Study

- Developing the research question and relevant outcomes to be studied
 - What outcomes are important to patients and care partners?
- Helping determine Inclusion/exclusion criteria
- Study design
 - Are the most appropriate patients able to be recruited?
 - Is there excessive burden on the patient?



Conducting the study

- Drafting or revising study materials and protocols
 - Helping with informed consent documents
- Participating in recruitment
 - Helping find participants
- Data collection and analysis
 - Can offer data analysis interpretations from a “lived-experience” perspective
 - “Theming” focus group content
 - Translating findings into patient language



Disseminating the Results

- Identifying best ways to disseminate results
 - Methods of dissemination – website, emails, presentations, news stories?
 - Location or Group – local support group, patient advocates?
- Participating in dissemination
 - May be included as authors or presenters



- Studio at work . . .
- Investigator presents project
- Investigator prepares list of questions for patients to discuss

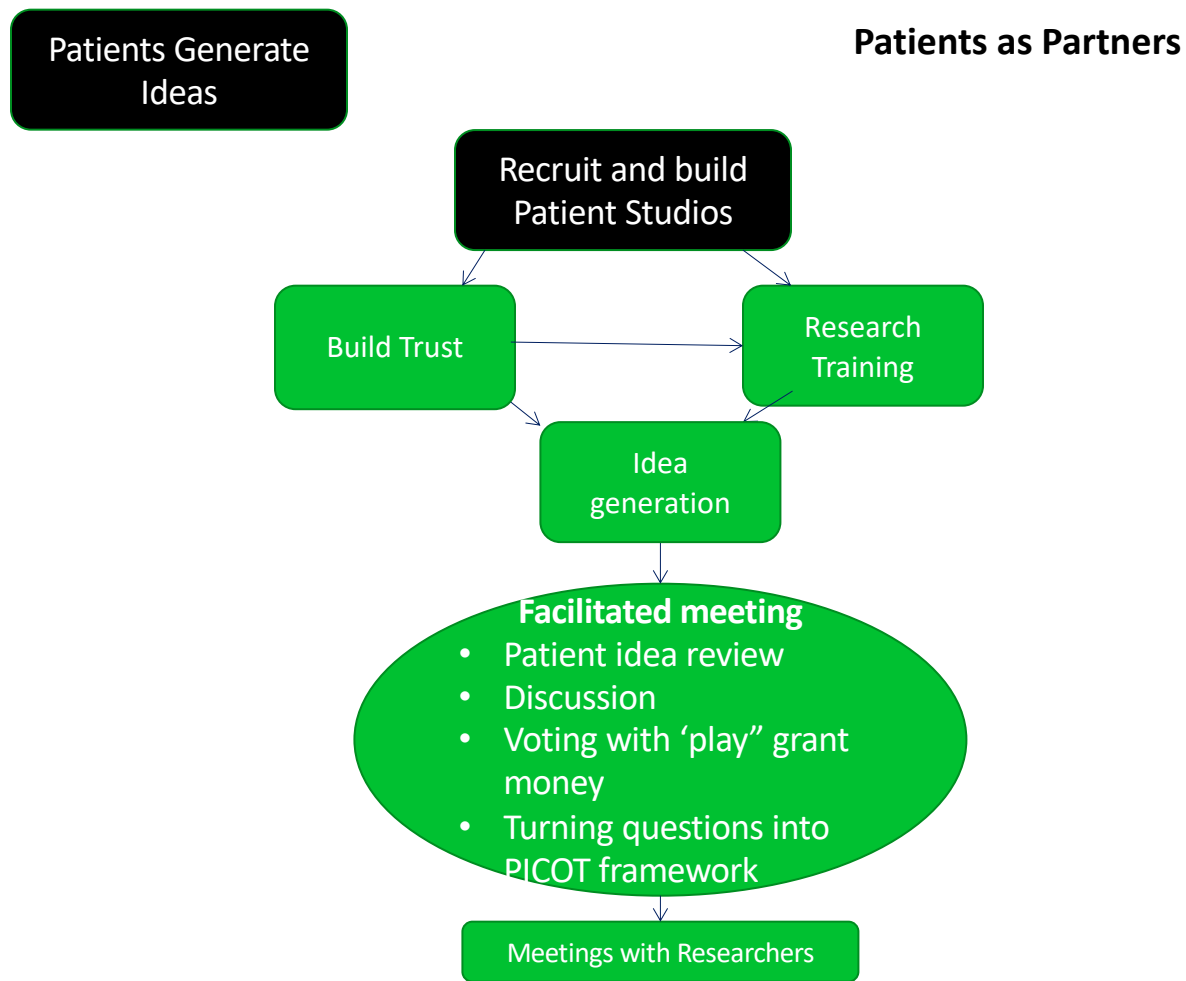


- Studio at work . . .
- Notes taken
- Report generated post studio by Studio Director with review by patients



- Studio at work . . .
- We listen . . .
- We discuss . . .
- We give ideas . . .





Based on model of Joosten et al, Academic Medicine, 2015.

A brief example of a patient conversation . . .

<https://www.ipfcc.org/bestpractices/strengthening-diversity/spotlight-videos.html>

Thanks for listening. Questions?

Contact Information . . .

Peggy Wagner, PhD

Distinguished Clinical Professor Emerita

Behavioral, Social, and Population Health Sciences

University of South Carolina School of Medicine Greenville

- wagnerpj@greenvillemed.sc.edu