Patient Engagement Studio
Involving Patients in Health Research and Innovation

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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
Patient Engagement Studio
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

Patient Engagement Panels
Patient as Partners
“Co-Investigators”

- Diagnostic/disease specific
- Patient involvement includes:
  - Planning
  - Conducting
  - Disseminating
- Patient represents all patient opinions

i.e. Focus Groups
Patients as Subjects
“Data Sources”

- Study specific
- Patient involvement includes:
  - Data and opinions: focus groups, surveys, social media
- Patient represents personal opinion
Researcher requests Studio review

Engagement Board reviews request

Clarify researcher questions

Determine stakeholder characteristics

Coach researcher - engagement of non-researchers

Create stakeholder-friendly presentation

Create “expert patient panel”

Pre-meeting orientation/training

Facilitated meeting
- Researcher presentation
- Stakeholder feedback
- Co-learning
- Evaluation

Written summary and feedback

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 . . .
Patients Generate Ideas

Recruit and build Patient Studios

- Build Trust
- Research Training
- Idea generation

Facilitated meeting
- Patient idea review
- Discussion
- Voting with ‘play” grant money
- Turning questions into PICOT framework

Meetings with Researchers

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 . . .

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