Putting the “Patient” into Patient-Centered Outcomes Research Prioritization

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Disclosures

- Patient-Centered Outcomes Research Institute (funding)
- Photocure (consultant)
Patient engagement is the blockbuster drug of the century.

– Farzad Mostashari
Patient-Centered Outcomes Research

- Benefits and Harms
- Questions & outcomes important to patients and caregivers
- Outcomes that matter
- Diversity
- Stakeholder Perspectives
Engaging Patients in Research

• Meaningful involvement of patients throughout research process
  – Influence research
  – Greater uptake of results
Theory is splendid but until put into practice, it is valueless.

JAMES CASH PENNEY
CO-FOUNDER, J.C. PENNEY
Patient Survey Network

- Engage bladder cancer patients and caregivers in research question prioritization
Recruit patients and caregivers to participate in the Patient Survey Network.
Generate research questions

Bladder Cancer Research Prioritization

1. Please list below comparative effectiveness of patients with non-muscle invasive bladder cancer.

For example:
What are the comparative adverse effects of different therapies?
What are the comparative benefits of continued medical therapy to cancer recurrence and progression?

What is the comparative effectiveness of...
Prioritize research questions

• Survey sent to PSN
  – Asked to rank 3 questions/disease stage
  – Free text research questions
• Stakeholder conference calls
• 660 participants PSN
• 361 survey respondents
Non-Muscle Invasive Research Questions

Questions Ranked First

- Question 1 (Reducing cysto discomfort) 47%
- Question 2 (Best medication after treatment failure?) 43%
- Question 3 (When to undergo bladder removal?) 10%
Muscle-Invasive Research Questions

Questions Ranked First

- Question 1 (Cystectomy vs. Bladder Sparing Treatment) - 60%
- Question 2 (Quality of life among urinary diversions) - 24%
- Question 3 (Best surveillance strategies after cystectomy) - 16%
Metastatic Research Questions

Questions Ranked First

- Question 1 (Comparing survival, side effects, QOL for different types of chemo)
- Question 2 (Timing of palliative care)
- Question 3 (Benefits of cystectomy + chemo vs. chemo alone)
WHO CARES??!!
Applications to GU Oncology

- Emergence of new research questions
- Repository for engaged patients
- Source for funding & engagement plans
- Funding sources available
“Health care is at the beginning of a dialogue with the world... as health care providers, we have to ask ourselves this question: What stories are we not hearing?”

– Sachin H. Jain
Patient Engagement Tips

• Level the playing field
• Creating community
• Believing in process
Level the Playing Field

- Pre-event interview
- Introduction at meeting
- Create norms and principles
- Guided storytelling
Creating Community

• Avoid having only one patient
• Respectfully prompt
• Share real-life examples of how patients and other stakeholders added value
• Provide feedback to participants
• Disseminate to research community
Key Points

• Engagement is foundation for PCO research
• Opportunities exist in GU Oncology
• Ensures long-term success
THANK YOU

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PATIENT PARTNERS
STAKEHOLDERS