SCOREboard Patient Advocate Board Presentation

Co-Chairs: Beverly Canin, Margaret Sedenquist
MPIs: Drs. William Dale, Arti Hurria, Supriya Mohile
Stakeholders for Care in Oncology and Research for our Elders Board (SCOREbord)

• Background
• Procedures
• CARinG SCOREboard
• Principles of Patient Engagement
• Questions
SCOREboard Background

• ASCO Annual Meeting 2011 and CARG
• PCORI COACH study – Communicating About Aging and Cancer Health
  Dr. Mohile
• 14 original members - patients 65 or older; caregivers of patients 65 or older; experienced patient advocates included but not limited to dyadys
• 3 California; 3 North Carolina; 6 New York;
  1 Illinois; 1 Connecticut
• 4 male; 2 African American; 11 cancer types;
  wide range of work experience
SCOREboard Procedures

• Monthly/bi-monthly 1.5 hour webinar meetings including the PI and other members of the research team

• Regular tasks – written and/or oral feedback on all aspects of study participant recruitment (fliers, consent forms), clinical research staff materials (guides, questionnaires, telephone follow-up)

• Co-authorship of manuscripts

• Excellent research team support staff for record keeping and facilitating all aspects of SCOREboard engagement
CARinG SCOREboard (goal 10 members)

• **Our Mission** – to improve aging and cancer research and care delivery by infusing the knowledge and experience of older patients with cancer and their caregivers in all stages of the research process.

• Current membership – 5 original members; 2 new confirmed; 1 pending (NC); 3 CA; 1 NC; 2 NY; 1 CT; 1 male (1 pending); 2 AA; 6 cancer types

• Seeking additional geographic diversity; Hispanic bi-lingual

• Procedures
  • 1.5 hour monthly webinar meetings including the liaison PI and members of the project team
  • One or two SCOREboard members work with each Core
Principles of Patient Engagement in Research

• PCORI Six Engagement Principles (patients/patient partners/stakeholders)
  • Reciprocal Relationships - collaborative decision-making
  • Co-learning – researchers help patients understand the research process while learning as patients share their perspectives
  • Partnerships – time and contributions of patients are valued; are shown; patient partners reflect the target population; diversity and cultural competency are shown
  • Transparency – share information with all research partners
  • Honesty – decisions made inclusively
  • Trust – commitment by all to open and honest communication
Questions?