

SCOREboard Patient Advocate Board Presentation

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Infrastructure Grant

Funded by NIH/NIA
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Stakeholders for Care in Oncology and Research for our Elders Board (SCOREbord)

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



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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 dyayds
- 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



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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



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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



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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



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Questions?



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