SCOREBOARD
SCOREboard Patient Advocate Board Presentation

Co-Chairs: Beverly Canin, Margaret Sedenquast

MPIs: Drs. William Dale, Supriya Mohile, Heidi Klepin
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 dyad
• 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
• Gilmore, Cancer, 2019
CARinG SCOREboard Members

- Beverly Canin (Co-chair)
- Margaret Sedenquist (Co-chair)
- Chuck Oshea (Member)
- Mary I. Whitehead (Member)
- Tomma Hargraves (Member)
- Gary Wallach (Member)
- Valerie Targia (Member)
- John Simmons (Member)
- Lewis Mustian (Member)

**Membership** – 9 active participants, including two co-chairs; 4 CA; 2 NC; 1 VA; 1 NY; 1 CT; 4 males/5 females; 6 cancer types
CARinG SCOREboard

• **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.

• **Structure**
  • 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
SCOREboard Procedures

• Monthly/bi-monthly 1.5 hour webinar meetings including one or more PIs from CARG, project PIs, 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; speakers for meetings

• Excellent research team support staff for record keeping and facilitating all aspects of SCOREboard engagement
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
**Metrics**

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<tr>
<th>Inquiry #</th>
<th>Date</th>
<th>First, Last Name:</th>
<th>Email Address:</th>
<th>Current Professional Role/Title:</th>
<th>Current Institution/Organization:</th>
<th>Projects</th>
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<tr>
<td>1</td>
<td>3/10/19</td>
<td>Melissa Kahl &amp; Linh</td>
<td><a href="mailto:melissa@umc.rochester.edu">melissa@umc.rochester.edu</a></td>
<td>D.O.</td>
<td>University of Rochester, NY</td>
<td>Examining older adults with breast cancer and cognition interventions - The Memory and Attention Adaptation Training (MAAT) intervention</td>
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<tr>
<td>2</td>
<td>5/1/19</td>
<td>Melanie Kahl &amp; Linh</td>
<td><a href="mailto:melissa@umc.rochester.edu">melissa@umc.rochester.edu</a></td>
<td>MBCH BAO, Senior Instructor</td>
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<td>Implementing GA in community oncology clinics - NCI Spirit Program</td>
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<td>3</td>
<td>10/22/19</td>
<td>Melissa Kahl &amp; Linh</td>
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<td>MBCH BAO, Senior Instructor</td>
<td>University of Rochester, NY</td>
<td>TouchStream (Innovate@UMC) Remote Care Mobile App to Deliver Geriatric Assessment-Driven Interventions</td>
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<tr>
<td>4</td>
<td>11/19/19</td>
<td>Meghan Kantor</td>
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<td>Developing a Decision Tool for Chemotherapy in Older Women with Early Stage Breast Cancer</td>
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<td>12/1/19</td>
<td>Karen L. Murfison</td>
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<td>1/1/20</td>
<td>Allison Magnussen</td>
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<td>M.D., M.S.</td>
<td>University of Rochester, NY</td>
<td>Development of a Personalized Decision Prioritization Tool (PDT) for Older Adults Considering Adjunct Chemotherapy for Breast Cancer</td>
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<td>2/18/20</td>
<td>Sushruta Gutiere</td>
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<td>M.D., M.S.</td>
<td>University of Rochester, NY</td>
<td>Limited PCORI Funding Announcement; Implementation of PCORI-Funded Patient-Centered Outcomes Research Studies</td>
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<tr>
<td>8</td>
<td>3/1/20</td>
<td>Lisa M. Lewenstein</td>
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<td>5/19/20</td>
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<td>6/16/20</td>
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<td>A Patient-Centered Communication Tool (PCCM) for Older Adults with Acute Myeloid Leukemia and Their Oncologists</td>
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<td>7/21/20</td>
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<td>9/1/20</td>
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<td>MB Anderson Cancer Center, Houston, TX; Implementing an Intervention to Address Concerns of Older Patients with Cancer Receiving Chemotherapy and Their Caregivers</td>
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<td>Medical Center, University of Rochester, NY; Development and Feasibility of a Supportive Care Intervention for Older Caregivers of Older Adults with Advanced Cancer</td>
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<td>14</td>
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<td>Shirley Rutherford</td>
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<td>Public Health Sciences, Director, Healthy Aging A, NCCN and NCI</td>
<td>NCCN Program and NCI Program</td>
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• Number of inquiries: 21 (Mar 2019 - Now)
Feedback from SCOREboard (minutes)

- **SCOREboard members Q&A**
  
  **Q1:** I can't imagine how I will follow it on an iPhone. I know you can get a stand, I don't use my phone much.
  
  A: Keep it close to your eyes and then on a chair in front, you don't have to see details after you get familiar about certain sessions because I've done it a few times and you can hear the instructor speaking. I can do it outdoors with my phone but the computer forces me to be home or I can drive a car and do it in the park. We intend to give both options with a computer or mobile phone. It becomes easier.

  **Q2:** This will measure effectiveness and recovery?
  
  A: This can be used to help us intervene in the recovery and use the same measures and outcomes like in a trial, and one of the things we could do is a questionnaire with social support and how it helps with experience. I can give you the questionnaire on the app and with this info in the background I can know how you interact within the community on this platform, and if you physically get some social supports.
**Ultimate Vision:** expand SCOREboard so that all members can work together like “CARG” SCOREboard

**CARG SCOREboard**
Patients, patient advocates, caregivers

**Members:** People who have participated or are interested in a role with cancer and aging research

**Chair:** Beverly Canin

**Meeting times:**
2 meetings vs. quarterly meetings for updates and opportunities for engagement

**Funding:**
R33? PCORI?

**Working groups:**
- Specific projects like PCORI study “COACH” and ongoing efforts
- Clinical efforts → implementation into the community
- Specific junior faculty projects
- R-level projects
- Could be linked to institutions dependent on leads/funding

**CARinG SCOREboard**

**Co-chairs:** Beverly Canin and Margaret Sedenquist

**Members:** Mary Whitehead, Valerie Targia, Tomma Hargraves, Gary Wallach, John Simmons

**Meet monthly to support CARG investigations/cores/members on cores**

**Engagement to build capacity**

CARG researchers and clinicians
Next Steps

• Seeking additional membership diversity (e.g., geographic, ethnic)
• Consider additional avenues for funding to support SCOREboard growth
• Develop training materials for new members and partners
• Continue to support activities and investigators in CARG
Questions?
CORE MEMBERS

Chair Co-Leads:
- Allison Magnuson, DO, MS
- Daniel Li MD
- Mina Sedrak, MD, MS

Board Members:
- Shelley Bluethmann, PhD
- Rawad Elias, MD
- Melissa Loh, MD
- Meghan Karuturi, MD
- Jessica Krok-Schoen, PhD
- Thuy Koll, MD
- Carolyn Presley, MD
- Manvi Sharma, RPh, PhD
- Ishwaria Subbiah, MD
- Melisa Wong, MD
MISSION

- Engage Junior Faculty in the CARinG mission, CARinG Infrastructure development, and CARinG Core activities
- Provide opportunities for direct Junior Faculty feedback on Infrastructure processes to ensure development is aligned with needs of early career investigators and CARG members
ACCOMPLISHMENTS

- Junior Faculty Board members have served as co-leads for CARG calls
  - Assist with developing content and agenda items
  - Develop and lead mentoring segments regularly during CARG calls

- Junior Faculty Board member involvement on other CARinG Cores
  - Co-Lead roles for other cores
<table>
<thead>
<tr>
<th>Name</th>
<th>Core</th>
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<tr>
<td>Allison Magnuson</td>
<td>Measures Core</td>
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<tr>
<td>Carolyn Presley</td>
<td>Supportive Care Core (Co-Lead)</td>
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<tr>
<td>Dan Li</td>
<td>Analytics Core</td>
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<tr>
<td>Grant Williams</td>
<td>Measures Core</td>
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<td>Ishwaria Subbiah</td>
<td>Communication Core (Co-Lead)</td>
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<tr>
<td>Jessica Krok-Schoen</td>
<td>Supportive Care Core</td>
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<tr>
<td>Manvi Sharma</td>
<td>Health Services Core</td>
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<tr>
<td>Meghan Karuturi</td>
<td>Health Services Core</td>
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<tr>
<td>Melisa Wong</td>
<td>Health Services Core (Co-Lead)</td>
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<td>Melissa Loh</td>
<td>Analytics Core</td>
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<td>Mina Sedrak</td>
<td>Analytics Core (Co-Lead)</td>
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<td>Rawad Elias</td>
<td>Clinical Implementation Core (Co-Lead)</td>
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<td>Shelley Bluethmann</td>
<td>Communication Core</td>
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<tr>
<td>Thuy Koll</td>
<td>Measures Core (Co-Lead)</td>
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ACCOMPLISHMENTS

- **Needs Assessment**
  - Survey of Junior Faculty Board members to understand barriers and facilitators for CARG engagement from the junior faculty perspective and opportunities to improve the experience of early career CARG members

- **Opportunity #1**: Transparency and inclusion -- overcoming bias and optimizing equal opportunities
- **Opportunity #2**: Limited engagement and structured career development activities
- **Opportunity #3**: Personalization -- how to engage clinical investigators, non-clinical scientists, educators, clinicians, etc. with different incentives and unmet needs
WHAT’S WORKING/WHAT’S NOT?

#1: Transparency and inclusion: overcoming bias and optimizing equal opportunities
- Form sub-interest groups and/or writing group sessions
- Transparency on the selection process
- CARG vs. non-CARG activities
- Formal vs. informal process

#2: Limited engagement and structured career development activities
- Smaller group discussion – junior calls quarterly option?
- Use slack, MS teams to communicate in real time
- Survey junior members
- More junior members to co-lead CARG meetings
- Allow more time on CARG meetings

#3: Personalization: how to engage clinical investigators, non-clinical scientists, educators, clinicians, etc. with different incentives and unmet needs
- Highlight non-clinicians in meetings (did you know …) – some favored and some did not
- Use website to connect one another
- Use newsletter promote non-clinicians
- Non-clinicians to meet and let us know how to support them
Flush out and finalize structure for enhanced mentoring component

***we would love input on this aspect!

Plan for rotation of core leadership and members
CARG ADVOCACY COMMITTEE
CARG Advocacy Committee

Presented by Armin Shahrokni, Beverly Canin, co-chairs
Jessica Krok-Schoen, member
Mission Statement

The CARG Advocacy Committee aims to improve the quality of care and outcomes of older adults with cancer through the identification of gaps in the quality and utilization of services and treatments accessed by this vulnerable population, with the determination to share our findings with the oncology community of clinicians, researchers and service providers, as well as policy makers and all stakeholders to ensure positive action is taken to improve infrastructures and resource allocation to directly address these gaps, and best serve older adults with cancer.
Early Initiatives

Efforts for policy change and recognition of issues of geriatric oncology at the local, national, and international level
- The Healthy Aging Policy Brief of the White House Conference on Aging
- Letter to former President Jimmy Carter
Current Membership

Main Results:

- Array of age distributions and varying categorization of “older adults”
- Inadequate reporting of treatment efficacy and adverse events
- Incorporating geriatric-specific outcomes and reporting the age-stratified data in a standardized and comprehensive manner can lead to better-informed treatment strategies
Main Results:

- 15% had written guidelines to manage older adults with cancer
- Respondents' degree of consideration for postponing or rescheduling treatment increased as age increased
- 86% that decision making about DNR orders should be shared with the patient and the healthcare proxy
Main Results:

- Healthcare system organizational challenges and meeting basic needs and support were commonly reported themes.

- Barriers to care delivery included organizational challenges, patients' access to resources and support, concerns for patients' mental and physical health, and telehealth challenges.

- Providers balanced their concerns for personal and patient safety.
Other Activities

“Racism and Ageism in the time of COVID19” webinar.
✓ July 28
✓ Talks by Drs. Reeder-Hayes and McKoy, followed by discussion about the advocacy efforts and CARG’s other activities.

External collaboration
SIOG and European colleagues.
ACCC
Future Advocacy Roadmap

Extending collaboration with other geriatric oncology advocacy groups both within and outside of the US.

More scholar activities with the focus on multidisciplinary advocacy efforts.

Updating CARG members and leadership regularly on Advocacy efforts.

Further promotion and encouragement of all stakeholders to join the Advocacy team.
How to Join Our Advocacy Efforts

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Shahroka@mskcc.org
CaninBeverly@gmail.com
CARing@coh.org

Website:
https://www.mycarg.org/?page_id=174