

A graphic consisting of a wide grey horizontal bar at the top, a vertical blue line on the left side, and another wide grey horizontal bar at the bottom. The word 'SCOREBOARD' is centered in the white space between the bars.

SCOREBOARD

SCOREboard Patient Advocate Board Presentation

Co-Chairs: **Beverly Canin, Margaret Sedenquist**

MPIs: Drs. William Dale, Supriya Mohile, Heidi Klepin



CARG

CANCER & AGING RESEARCH GROUP

Infrastructure Grant

Funded by NIH/NIA

Grant No. 1R21AG059206

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 dyads
- 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



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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



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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



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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



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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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Metrics

Inquiry #	Date	First, Last Name:	Email Address:	Current Professional Role/Title:	Current Institution/Organization:	Projects
1	3/20/19	Allison Magnuson	on_Magnuson@URMC.Rochester.edu	D.O.	University of Rochester, NY	Examining older adults with breast cancer and cognition interventions - The Memory and Attention Adaptation Training (MAAT) intervention
2	5/21/19	Melissa (Kah Poh) Loh	ahpoh_Loh@URMC.Rochester.edu	MBBCh BAO, Senior Instructor	University of Rochester, NY	Implementing GA in community oncology clinics - NCI Sprint Program
3	10/22/19	Melissa (Kah Poh) Loh		MBBCh BAO, Senior Instructor	University of Rochester, NY	TouchStream (now PointClickCare® Remote Care) Mobile App to Deliver Geriatric Assessment-Driven Interventions
4	11/19/19	Meghan Karuturi		Assistant Professor	Department of Breast Medical Oncology, Division	Developing a Decision Tool for Chemotherapy in Older Women with Early Stage Breast Cancer
5	12/17/19	Karen M. Mustian	ren.Mustian@URMC.Rochester.edu	Professor	Department of Surgery, URCC NCORP, University	YOCAS: Yoga for Cancer Survivors
6	1/21/20	Allison Magnuson		D.O.	University of Rochester, NY	Development of a Personalized Discussion Prioritization Tool(DPT) for Older Adults Considering Adjuvant Chemotherapy for Breast Cancer
		Mina S. Sedrak	msedrak@coh.org	M.D., M.S	City of Hope, Duarte, CA	
7	2/18/20	Supriya G. Mohile	supriya.Mohile@URMC.Rochester.edu	M.D., M.S	University of Rochester, NY	Limited PCORI Funding Announcement: Implementation of PCORI-Funded Patient-Centered Outcomes Research Results
		Lisa M. Lowenstein	LMLowenstein@mdanderson.org	PhD, MPH, RD	MD Anderson Cancer Center, Houston, TX	
8	3/17/20	Melissa (Kah Poh) Loh		MBBCh BAO, Senior Instructor	University of Rochester, NY	A Patient-Centered Communication Tool (UR-GOAL) for Older Adults with Acute Myeloid Leukemia and Their Oncologists
9	5/19/20	Charles S. Kamen	charles.Kamen@URMC.Rochester.edu	Ph.D. Assistant Professor	Department of Surgery, University of Rochester	COE Grant: Community Outreach and Engagement at the Wilmot Cancer Institute
		Ana-Paula Cupertino	la.Cupertino@URMC.Rochester.edu	Ph.D. Professor	Department of Public Health Sciences, University of Rochester, NY	
10	6/16/20	Gina Grantham	Gina.Grantham@conquer.org	Senior Manager	Healthcare Relations and Grants, Conquer Cancer	Conquer Cancer Foundation Webinar
11	7/21/20	Karen M. Mustian		Professor	Department of Surgery, URCC NCORP, University	YOCAS Platform
		Abraham (Avi) Seidmann	AVIS@bu.edu	Ph.D. Professor	Boston University	
12	9/15/20	Lisa M. Lowenstein	LMLowenstein@mdanderson.org	PhD, MPH, RD	MD Anderson Cancer Center, Houston, TX	Implementing an Intervention to Address Concerns of Older Patients with Cancer Receiving Chemotherapy and Their Caregivers
13		Sindhujaa Kadambi	hujaa.Kadambi@URMC.Rochester.edu	Geriatric Medicine Fellowship	Medical Center, University of Rochester, NY	Development and Feasibility of a Supportive Care Intervention for Older Caregivers of Older Adults with Advanced Cancer
15	11/17/20	Supriya G. Mohile		M.D., M.S	University of Rochester, NY	Older adult cancer survivors in rural areas for a mixed methods project
		Evelyn Arana	evelyn.Arana@URMC.Rochester.edu	M.S., Dr.P.H. Research Assistant Professor	Department of Public Health Sciences (SMD), University of Rochester	
16	12/8/20	Erika E. Ramsdale	erika.Ramsdale@URMC.Rochester.edu	M.D. Assistant Professor	Department of Medicine, University of Rochester	Listening Session/Focus Group: Medication Use in Older Adults with Cancer
17	1/19/21	Daniel Richardson	daniel_richardson@med.unc.edu	Assistant Professor, Leukemia Program	University of North Carolina	Treatment Decision-Making in Older Adults with Acute Myeloid Leukemia: What is the goal?
18	2/16/21	Melissa (Kah Poh) Loh		MBBCh BAO, Senior Instructor	University of Rochester, NY	A Telehealth Advanced Care Planning Intervention for Older Patients with Acute Myeloid Leukemia and Myelodysplastic Syndrome
19		Katherine Clifton	k.clifton@wustl.edu	Assistant Professor	Washington University School of Medicine	CARG pilot grant
20		Tina Hsu	tina.hsu@medportal.ca	M.D.	Ottawa Hospital	the second Canadian geriatric oncology meeting
21		Shirley Bluethmann	szb332@psu.edu	Assistant Professor	Public Health Sciences, Director, Healthy Aging A	IRB Questions and Focus Group

- Number of inquiries: 21 (Mar 2019 - Now)



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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.



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Umbrella Development

Meeting times:

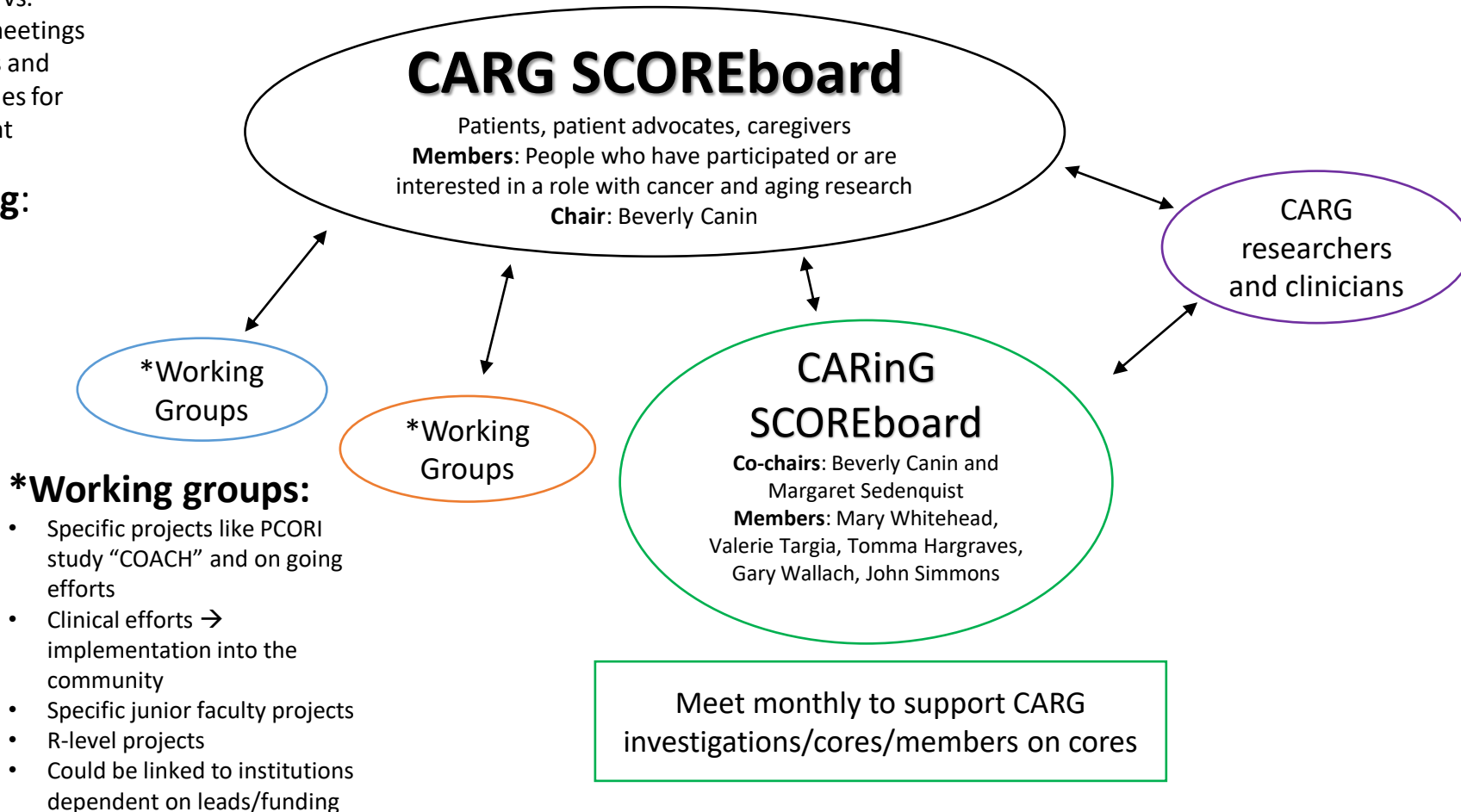
2 meetings vs. quarterly meetings for updates and opportunities for engagement

Funding:

R33?
PCORI?

Ultimate Vision: expand SCOREboard so that all members can work together like “CARG” SCOREboard

Engagement to build capacity



*Working groups:

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

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



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Questions?



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JUNIOR INVESTIGATOR BOARD

JUNIOR INVESTIGATOR BOARD

DRS. ALLISON MAGNUSON, MINA SEDRAK & DAN LI



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

Name**Core**

Allison Magnuson	Measures Core
Carolyn Presley	Supportive Care Core (Co-Lead)
Dan Li	Analytics Core
Grant Williams	Measures Core
Ishwaria Subbiah	Communication Core (Co-Lead)
Jessica Krok-Schoen	Supportive Care Core
Manvi Sharma	Health Services Core
Meghan Karuturi	Health Services Core
Melisa Wong	Health Services Core (Co-Lead)
Melissa Loh	Analytics Core
Mina Sedrak	Analytics Core (Co-Lead)
Rawad Elias	Clinical Implementation Core (Co-Lead)
Shelley Bluethmann	Communication Core
Thuy Koll	Measures Core (Co-Lead)

ACCOMPLISHMENTS

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

FUTURE DIRECTION

- *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

Armin Shahrokni, Co-chair, Beverly Canin, Co-chair,
Jessica Krok-Schoen, Karlynn BrintzenhofeSzoc,
Amy MacKenzie, Leana Chien, Nicolo Battisti, Hussai
Nuristani, Mackenzi Pergolotti, Mariuxi Malone,
Arifa Abid, Meghan Karuturi, Nikesha Gilmore,
Imran Ali

Publications

Published in final edited form as:

J Geriatr Oncol. 2020 April ; 11(3): 369–379. doi:10.1016/j.jgo.2019.12.007.

The underreporting of phase III chemo-therapeutic clinical trial data of older patients with cancer: A systematic review

Karlynn BrintzenhofeSzoc^{a,*},¹, Jessica L. Krok-Schoen^b,¹, Beverly Canin^c, Ira Parker^d, Amy R. MacKenzie^e, Thuy Koll^f, Ritika Vankina^g, Christine D. Hsu^h, Brian Jangⁱ, Kathy Pan^g, Jennifer L. Lund^h, Edith Starbuck^j, Armin Shahrokni^k

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

Publications



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

Publications



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

Email:

Shahroka@mskcc.org

CaninBeverly@gmail.com

CARing@coh.org

Website:

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