Future Directions in Cancer Survivorship Research

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Interim Director, Office of Cancer Survivorship
Using WebEx and Webinar Logistics

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- This webinar is being recorded
The specific goals of this webinar are:

1) to present the research gaps in the recommended components of survivorship care and important next steps that were identified at a recent NCI meeting; and

2) to gather feedback on the identified strategic research priorities.
Planning Committee

Internal:
Janet de Moor, PhD, MPH;
Margaret Farrell, MPH, RD;
Lisa Gallicchio, PhD;
Paige Green, PhD, MPH, FABMR;
Deborah Mayer, PhD, RN, AOCN, FAAN;
Nicole Saiontz, MHS; and Li Zhu, PhD

External:
Julia Rowland, PhD
Catherine Alfano, PhD

Facilitator: Trish Silber, Aliniad

1. Keynote
2. Prevention and surveillance for recurrences and new cancers
3. Management of Long-term and Late Effects: Physical
4. Management of Long-term and Late Effects: Psychosocial
5. Health Promotion
6. Care Coordination
7. Economic Effects
Questions Posed

Pre-reading for group:


1. What are the most important gaps in cancer survivorship care research that need to be addressed?

2. What are the most important strategic research priorities to address these gaps?

3. What are the key next steps to generate meaningful progress soon?
Keynote: Kevin Oeffinger, MD
Duke University
Challenges to Survivorship Care

- Number of NIH-funded studies in survivorship care has increased but still low; K awards increased from 20→43 over last 10 years
- Integrating PCP across and throughout cancer care continuum
- Literature exists on impact of treatment exposure on long-term/late effects but small number of intervention studies

- Impact of large volume of survivors in health care delivery
- Shift to value-based care
- Role of risk-stratified follow-up care
- Potential for AHRQ Practice-Based Research Networks (PBRN) in Primary Care and NCI Community Oncology Research Program (NCORP) sites to collaborate?
# The Cancer Control Continuum

## Focus

<table>
<thead>
<tr>
<th>Etiology</th>
<th>Prevention</th>
<th>Detection</th>
<th>Diagnosis</th>
<th>Treatment</th>
<th>Survivorship</th>
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<tbody>
<tr>
<td>Environmental factors</td>
<td>Tobacco control</td>
<td>Pap/HPV testing</td>
<td>Shared and informed decision making</td>
<td>Curative treatment</td>
<td>Surveillance</td>
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<td>Genetic factors</td>
<td>Diet</td>
<td>Mammography</td>
<td>Non-curative treatment</td>
<td>Non-curative treatment</td>
<td>Physical effects</td>
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<tr>
<td>Gene-environment interactions</td>
<td>Physical activity</td>
<td>Fecal occult blood test</td>
<td>Adherence</td>
<td>Psychological treatment</td>
<td>Psychosocial effects</td>
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<tr>
<td>Medication (or pharmaceutical exposure)</td>
<td>Sun protection</td>
<td>Colonoscopy</td>
<td>Symptom management</td>
<td>Health promotion</td>
<td>Economic effects</td>
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<tr>
<td>Infectious agents</td>
<td>HPV vaccine</td>
<td>Lung cancer screening</td>
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<td>Health behaviors</td>
<td>Limited alcohol use</td>
<td>Chemoprevention</td>
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## Cross Cutting Themes

- Reducing disparities in survivorship care
- Exploit existing datasets and studies to include survivorship
- How to leverage technology for measurement and intervention
- Need for multilevel studies while keeping patient-centered
- Implementation into the community
- Risk based stratified models

Adapted from David B. Abrams, Brown University School of Medicine
Prevention and Surveillance for Recurrences and New Cancers

Jamie Goldfarb, survivor and research advocate
Ronald Chen, MD, MPH, University of North Carolina
Joanne Elena, PhD, MPH, National Cancer Institute
Surveillance Research Priorities

- Surveillance schedules
  - Testing optimal frequency, risks and benefits and bundled screening
  - Evidence-based guidelines consistent across organizations
- Reducing disparities among different populations
- Adding longer surveillance for existing, relevant clinical trials
- Enhancing SEER, State Registries and National Cancer Databases
Survey/feedback question on priorities

- POLL: Would you consider these to be the top strategic research priority in the area?
  - A. Strongly agree
  - B. Somewhat agree
  - C. Neither agree or disagree
  - D. Somewhat disagree
  - E. Strongly disagree

- CHAT: What do you consider to be the top research priority in the area of Prevention and Surveillance for Recurrences and New Cancers?
Management of Long-Term and Late Effects: Physical

Craig Lustig, MPA, Lombardi Cancer Center
Ann Berger, PhD, APRN-CNS, AOCNS, FAAN
University of Nebraska
Sandra Mitchell, PhD, CRNP, FAAN
National Cancer Institute
Physical Late/Long-term Research Priorities

- Measurement of symptoms, functional impairments, comorbid conditions and needs as core measures by disease
- Profiles of natural history of late/long-term effects in prevalent cancers
- Frame intervention development using chronic disease model (CDM) as it is multilevel and is patient and family focused at its core and spans risk reduction, rehabilitation and self-management support
Survey/feedback question on priorities

- POLL: Would you consider these to be the top strategic research priority in the area?
  - A. Strongly agree
  - B. Somewhat agree
  - C. Neither agree or disagree
  - D. Somewhat disagree
  - E. Strongly disagree

- CHAT: What do you consider to be the top research priority in the area of Management of Long-Term and Late Effects: Physical?
Management of Long-Term and Late Effects: Psychosocial

Linda House
Cancer Support Community
Karen Syrjala, PhD
Fred Hutchinson Cancer Research Center and University of Washington
Paige Green, PhD, MPH, FABMR
National Cancer Institute
Psychosocial Late/Long-term Research Priorities

- Implementation of psychosocial interventions in real-world settings (e.g. community oncology, primary care) → integration of psychosocial services into existing community systems.

- Prevention and mitigation strategies that include risk-stratification
Survey/feedback question on priorities

- POLL: Would you consider these to be the top strategic research priority in the area?
  - A. Strongly agree
  - B. Somewhat agree
  - C. Neither agree or disagree
  - D. Somewhat disagree
  - E. Strongly disagree

- CHAT: What do you consider to be the top research priority in the area of Management of Long-Term and Late Effects: Psychosocial?
Health Promotion

Brittany Avin, PhD(c), survivor and research advocate
Johns Hopkins University
Karen Basen-Engquist, PhD, MPH
MD Anderson Cancer Center
Frank Perna, EdD, PhD
National Cancer Institute
Health Behavior Research Priorities

- Mechanisms and biomarkers for health behaviors
- Integration of exiting and emerging technologies for health promotion in cancer survivorship care
- Multi-level research studies addressing health behaviors in cancer survivors
Survey/feedback question on priorities

- POLL: Would you consider these to be the top strategic research priority in the area?
  - A. Strongly agree
  - B. Somewhat agree
  - C. Neither agree or disagree
  - D. Somewhat disagree
  - E. Strongly disagree

- CHAT: What do you consider to be the top research priority in the area of Health Promotion?
Care Coordination

Shelley Fuld Nasso, MPP
National Coalition for Cancer Survivorship
Shawna Hudson, PhD
Robert Wood Johnson Medical School - Rutgers University
Michelle Mollica, PhD, MPH, RN, OCN
National Cancer Institute
Care Coordination Research Priorities

- Identify key outcomes to assess quality care coordination
- What are optimal models to promote risk-based care coordination?
  - What are key strategies to support vulnerable populations?
- How to engage IT in care coordination
Survey/feedback question on priorities

- POLL: Would you consider these to be the top strategic research priority in the area?
  - A. Strongly agree
  - B. Somewhat agree
  - C. Neither agree or disagree
  - D. Somewhat disagree
  - E. Strongly disagree

- CHAT: What do you consider to be the top research priority in the area of Care Coordination?
Economic Effects

Robin Yabroff, PhD
American Cancer Society
Janet de Moor, PhD, MPH
National Cancer Institute
Economic Research Priorities

- Longitudinal studies to understand risk factors for financial hardship, employment limitations and other economic effects.
- Studies to understand the impact of financial hardship, employment limitations and other economic effects on functioning, clinical outcomes, quality of life and healthcare utilization.
- Conduct new interventions to address economic effects and leveraging implementation science to ensure effective interventions are disseminated.
- Leverage data infrastructure, linkages, and methods
- Leverage technology to collect data and deliver interventions.
Survey/feedback question on priorities

- POLL: Would you consider these to be the top strategic research priority in the area?
  - A. Strongly agree
  - B. Somewhat agree
  - C. Neither agree or disagree
  - D. Somewhat disagree
  - E. Strongly disagree

- CHAT: What do you consider to be the top research priority in the area of Economic Effect?
Next Steps
Recent NCI Survivorship Funding Announcements

- RFA-CA-19-033: Improving Outcomes for Pediatric, Adolescent and Young Adult Cancer Survivors (U01 Clinical Trial Required)

- RFA CA-19-035: Optimizing the Management and Outcomes for Cancer Survivors Transitioning to Follow-up Care

- Others listed at
  - https://cancercontrol.cancer.gov/funding_apply.html#ocs
  - https://grants.nih.gov/funding/index.htm