NATIONAL ACADEMIES Sciences Engineering Medicine

May 2022

Dear Colleagues:

Welcome to the workshop on *Family Caregiving for People with Cancer and Other Serious Illnesses,* hosted by the Roundtable on Quality Care for People with Serious Illness, the National Cancer Policy Forum, and the Forum on Aging, Disability, and Independence at the National Academies of Sciences, Engineering, and Medicine.

This workshop unfolds across six sessions of a day-and-a-half-long program. A Keynote Address by Greg Link, Director of the Office of Supportive and Caregiving Services at HHS' Administration for Community Living opens the workshop. The second session of the workshop explores the diverse needs of family caregivers, followed by a session highlighting examples of programs designed to address those needs. The fourth session examines effective ways to integrate family caregivers into the health care team. Research challenges and opportunities are explored in the fifth session. The workshop closes with a discussion of policy opportunities to support family caregivers. The voices and lived experiences of family caregivers are interwoven throughout all sessions of the workshop.

The workshop sessions include a mix of presentations, panel discussions and Q&A with workshop participants. A summary of this workshop will be published by the National Academies Press. The webinar's meeting materials as well as a video archive of the webinar will be available at: https://www.nationalacademies.org/event/05-16-2022/family-caregiving-for-people-with-cancer-and-other-serious-illnesses-a-workshop

We hope you will find the workshop presentations informative, thought-provoking, and inspiring, and that the suggestions made by the workshop participants will ultimately contribute to improving support for family caregivers who provide care for people of all ages and all stages of serious illness.

Sincerely,

Grace Campbell, PhD, MSW, RN

Assistant Professor
Duquesne University School of Nursing
Director of Quality and System Integration, Family CARE Center
Gynecologic Oncology Program,
Hillman Cancer Center at UPMC

Randall A. Oyer, MD, FACCC

Clinical Professor of Medicine
Perelman School of Medicine
Executive Medical Director
Ann B. Barshinger Cancer Institute
Penn Medicine
Lancaster General Health

NATIONAL ACADEMIES Sciences Engineering Medicine

ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS
NATIONAL CANCER POLICY FORUM
FORUM ON AGING, DISABILITY, AND INDEPENDENCE

# Family Caregiving for People with Cancer and Other Serious Illnesses

## WEBCAST INFORMATION FOR ATTENDEES

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Join the live webstream of the workshop via the link below:
https://www.nationalacademies.org/event/05-16-2022/family-caregiving-for-people-with-cancer-and-other-serious-illnesses-a-workshop

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- This workshop is being webcast and recorded. The webcast and presentation files will be archived on the project webpage.
- We welcome your involvement in the workshop. Please use the chatbox (located below the livestream video box) to submit questions, and include your name and affiliation.
- Please use the hashtags **#SeriousIllnessCareNASEM**, **#AgingDisabilityForum**, and **#NatlCancerForum** to tweet about the workshop.
- Proceedings of the workshop will be published following National Academies procedures. Rapporteurs will compose the proceedings from the workshop transcript and external reviewers will examine the proceedings to make sure it accurately reflects workshop discussions and conforms to institutional policies.

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To receive updates on upcoming events:

Sign up for the **Roundtable on Quality Care for People with Serious Illness** listserv at:
https://www.nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable.aspx

Sign up for the **National Cancer Policy Forum** listserv at:
https://www.nationalacademies.org/our-work/national-cancer-policy-forum

Sign up for the **Forum on Aging, Disability, and Independence** at:
https://www.nationalacademies.org/our-work/forum-on-aging-disability-and-independence

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NATIONAL ACADEMIES Sciences Engineering Medicine

# FAMILY CAREGIVING FOR PEOPLE WITH CANCER AND OTHER SERIOUS ILLNESSES
# A WORKSHOP

**ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS**

**NATIONAL CANCER POLICY FORUM**

**FORUM ON AGING, DISABILITY AND INDEPENDENCE**

**The Keck Center of The National Academies**
**Washington, D.C.**
**May 16-17, 2022**

| **WORKSHOP AGENDA DAY ONE**<br>**Monday May 16, 2022** | |
|---|---|
| **8:00 AM** | **REGISTRATION AND BREAKFAST** |
| **8:30 AM** | **WELCOME TO THE WORKSHOP**<br><br>Peggy Maguire, JD<br>President and Board Chair, Cambia Health Foundation<br><br>James Tulsky, MD<br>Chair, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute; Chief, Division of Palliative Medicine, Department of Medicine, Brigham and Women's Hospital; Co-Director, Harvard Medical School Center for Palliative Care; and Professor of Medicine, Harvard Medical School<br><br>Co-Chairs, *Roundtable on Quality Care for People with Serious Illness* |
| **8:45 AM** | **OVERVIEW OF THE WORKSHOP**<br><br>Grace Campbell, PhD, MSW, RN<br>Assistant Professor, Duquesne University School of Nursing<br>Director of Quality and System Integration, Family CARE Center Gynecologic Oncology Program, Hillman Cancer Center at UPMC Magee<br><br>Randall A. Oyer, MD, FACCC<br>Clinical Professor of Medicine, Perelman School of Medicine<br>Executive Medical Director, Ann B. Barshinger Cancer Institute<br>Penn Medicine<br>Lancaster General Health<br><br>*Planning Committee Co-Chairs* |

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| **9:00 AM** | **SESSION ONE: THE LANDSCAPE OF FAMILY CAREGIVING**<br><br>*Moderator:*<br>*Julie Bynum, MD, MPH*<br>*Margaret Terpenning Professor of Medicine, Division of Geriatric Medicine*<br>*University of Michigan*<br><br>**Keynote Speaker**<br>Greg Link, MA<br>Director, Office of Supportive and Caregiving Services<br>Administration for Community Living, U.S. Department of Health and Human Services |
| **9:25 AM** | *"Reactor" Panelists:*<br><br>**Sheria Robinson-Lane,** PhD, MSN, MHA, RN<br>Assistant Professor<br>University of Michigan School of Nursing<br><br>**Loretta Christensen,** MD, MBA<br>Chief Medical Officer, Indian Health Service (participating remotely) |
| **9:40 AM** | **MODERATED DISCUSSION/Q&A SESSION** |
| **10:15 AM** | **BREAK** |
| **10:30 AM** | **SESSION TWO: UNDERSTANDING THE NEEDS OF FAMILY CAREGIVERS**<br><br>*Co-Moderators:*<br>*Jennifer Moore Ballentine, MA*<br>*Executive Director*<br>*CSU Shiley Haynes Institute for Palliative Care*<br><br>*Rebecca Kirch, JD*<br>*Executive VP, Policy and Programs*<br>*National Patient Advocate Foundation*<br><br>*Speakers:*<br><br>Kimberly D. Acquaviva, PhD, MSW, CSE, FNAP<br>Betty Norman Norris Endowed Professor<br>University of Virginia School of Nursing<br><br>Cathy J. Bradley, PhD<br>Professor and Associate Dean for Research,<br>Colorado School of Public Health, University of Colorado at Denver<br>Deputy Director, University of Colorado Comprehensive Cancer Center |

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|---|---|
| | Alexandra Drane<br>Co-Founder and CEO<br>ARCHANGELS<br><br>Wendy G. Lichtenthal, PhD, FT<br>Director, Bereavement Clinic<br>Associate Attending Psychologist<br>Department of Psychiatry and Behavioral Sciences<br>Memorial Sloan Kettering Cancer Center<br><br>Dannell Shu, BFA, MWS<br>Family Caregiver, Pediatric Palliative Care National Task Force<br>Member, Minnesota Department of Health's Palliative Care Advisory Council |
| **11:35 AM** | **AUDIENCE Q&A** |
| **12:00 PM** | **Break for LUNCH** |
| **1:00 PM** | **SESSION THREE: PROVIDING EFFECTIVE SUPPORT FOR FAMILY CAREGIVERS**<br><br>*Co-Moderators:*<br>*Randy Jones, PhD, RN, FAAN*<br>*Professor and Associate Dean,*<br>*Partner Development and Engagement, University of Virginia School of Nursing*<br>*Assistant Director of Outreach, Recruitment, and Engagement*<br>*University of Virginia Comprehensive Cancer Center*<br><br>*Clyde W. Oden, Jr., OD, MDiv, MPH, MBA*<br>*Assistant Director, Alameda County Care Alliance*<br><br>*Speaker/Caregiver Dyads:*<br><br>Fayron Epps, PhD, RN, FAAN<br>Assistant Professor<br>NHCGNE Distinguished Educator in Gerontological Nursing<br>Nell Hodgson Woodruff School of Nursing, Emory University<br>Founder, Alter<br><br>Malcoma Brown-Ekeogu<br>Family Caregiver and Advocate for Frontotemporal Dementia (FTD) care<br><br>Allison J. Applebaum, PhD<br>Associate Attending Psychologist<br>Director, Caregivers Clinic, Department of Psychiatry and Behavioral Sciences<br>Memorial Sloan Kettering Cancer Center<br><br>Peter Gee, MPP<br>Family Caregiver<br>Nursing student, NYU School of Nursing (participating remotely) |

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|---|---|
| | Loretta Christensen, MD, MBA<br>Chief Medical Officer, Indian Health Service (participating remotely)<br><br>Elton Becenti, Jr. (participating remotely)<br>Family Caregiver<br><br>Janice F. Bell, PhD, MPH, MN, FAAN (participating remotely)<br>Associate Dean for Research, Doctor of Philosophy Program Director<br>Western Health Advantage Endowed Professor and Professor<br>Founding Faculty Member, Family Caregiving Institute<br>Betty Irene Moore School of Nursing, University of California at Davis<br>Lead Evaluator, Alameda County Care Alliance<br><br>Lyn-Tise Jones, MA (participating remotely)<br>Family Caregiver and Care Navigator<br><br>Heidi Donovan, PhD, RN<br>Professor of Nursing and Medicine<br>Co-Director, National Rehabilitation Research & Training Center on Family Support, University of Pittsburgh<br>Director, GynOnc Family CARE Center, Magee Womens-Hospital of UPMC<br><br>Roger Glen Kirwin<br>Family Caregiver |
| **2:40 PM** | **MODERATED Q & A** |
| **3:00 PM** | **BREAK** |
| **3:15 PM** | **SESSION FOUR: INTEGRATING FAMILY CAREGIVERS INTO THE HEALTH CARE TEAM**<br><br>*Co-Moderators:*<br>*Sara Damiano, LCSW, ACHP-SW*<br>*National Director of Palliative Care, Ascension*<br><br>*Allison J. Applebaum, PhD*<br>*Memorial Sloan Kettering Cancer Center*<br><br>Speakers/Panelists:<br><br>Jason Karlawish, MD<br>Senior Fellow, Leonard Davis Institute of Health Economics<br>Professor of Medicine,<br>Perelman School of Medicine<br>Co-director, Penn Memory Center<br>University of Pennsylvania |

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| | Courtney Harold Van Houtven, PhD, MSc<br>Research Career Scientist, Center of Innovation to Accelerate Discovery and Practice Transformation (ADAPT), Durham Veterans Affairs Health Care System<br>Professor in The Department of Population Health Science<br>Duke University School of Medicine and Duke-Margolis Center for Health Policy<br><br>Terri Fried, MD<br>Professor of Medicine, Section Chief, Geriatric Medicine<br>Yale University School of Medicine<br><br>Catherine M. DesRoches, DrPH<br>Associate Professor of Medicine<br>Harvard Medical School<br>Director, OpenNotes<br>Beth Israel Deaconess Medical Center |
| **4:00 PM** | **MODERATED DISCUSSION** |
| **4:30 PM** | **AUDIENCE Q&A** |
| **4:50 PM** | **Workshop Day One Wrap-Up** |
| **5:00 PM** | **Workshop Day One Adjourns**<br><br>**RECEPTION IN THE ATRIUM** |
| **WORKSHOP DAY TWO<br>Tuesday May 17, 2022** | |
| **8:00 AM** | **REGISTRATION AND BREAKFAST** |
| **8:30 AM** | **Welcome from the Planning Committee Co-Chairs**<br><br>*Grace Campbell and Randy Oyer*<br><br>– Brief Review of key themes from Workshop Day One<br>– Overview of Workshop Day Two |
| **8:45 AM** | **SESSION FIVE: RESEARCH CHALLENGES AND OPPORTUNITIES**<br><br>*Co-Moderators:*<br>*Pamela S. Hinds, PhD, RN, FAAN*<br>*Executive Director, Department of Nursing Science*<br>*Professional Practice & Quality Research Integrity Officer, Children's National Hospital*<br>*Professor of Pediatrics, School of Medicine and Health Sciences*<br>*George Washington University*<br><br>*Cathy J. Bradley, PhD*<br>*Professor and Associate Dean for Research,*<br>*Colorado School of Public Health, University of Colorado at Denver*<br>*Deputy Director, University of Colorado Comprehensive Cancer Center* |

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|---|---|
| | *Speakers:*<br><br>Rebekah SM Angove, PhD<br>Vice President, Patient Experience and Program Evaluation<br>Director, Patient Insight Institute, Patient Advocate Foundation<br><br>Jennifer L. Wolff, PhD<br>Eugene and Mildred Lipitz Professor<br>Director, Roger C. Lipitz Center for Integrated Health Care<br>Department of Health Policy and Management<br>Johns Hopkins Bloomberg School of Public Health<br><br>Erin E. Kent, PhD, MS<br>Associate Professor, Department of Health Policy and Management<br>UNC Gillings School of Global Public Health<br>Member of the Lineberger Comprehensive Cancer Center<br>Prevention and Control Program<br><br>Sheria Robinson-Lane, PhD, MSN, MHA, RN<br>Assistant Professor<br>Department of Systems, Populations, and Leadership<br>University of Michigan School of Nursing |
| **9:30 AM** | **MODERATED DISCUSSION** |
| **10:00 AM** | **AUDIENCE Q&A** |
| **10:20 AM** | **SESSION SIX: POLICY OPPORTUNITIES TO SUPPORT FAMILY CAREGIVERS**<br><br>*Co-Moderators:*<br>*Amy Melnick, MPA*<br>*Executive Director,*<br>*National Coalition for Hospice and Palliative Care*<br><br>*Rani E. Snyder, MPA*<br>*Vice President, Programs*<br>*The John A. Hartford Foundation*<br><br>*Panelists:*<br><br>Susan Reinhard, RN, PhD, FAAN<br>Senior Vice President and Director, AARP Public Policy Institute & Chief Strategist, Center to Champion Nursing in America and Family Caregiving Initiatives<br><br>Devin Plote, PhD<br>Clinical Policy Analyst, Clinical Innovation<br>America's Health Insurance Plans |

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|---|---|
| | Michael Reese-Wittke, MPA<br>Vice President for Advocacy and Research<br>National Alliance for Caregiving<br><br>Salom Teshale, PhD<br>Policy Associate, Behavioral Health, Aging and Disability<br>National Academy for State Health Policy |
| **11:20 AM** | **AUDIENCE Q AND A** |
| **11:40 AM** | **Workshop Wrap-up**<br>Grace Campbell and Randall Oyer<br>*Planning Committee Co-Chairs* |
| **11:45 AM** | **Closing Remarks**<br>Abena Apau Buckley, MBA<br>*Family Caregiver*<br>*Farm Production and Conservation*<br>*US Department of Agriculture*<br><br>Dannell Shu, BFA, MWS<br>*Family Caregiver*<br>*Pediatric Palliative Care National Task Force*<br>*Member, Minnesota Department of Health's Palliative Care Advisory Council* |
| **12:00 PM** | **Workshop Adjourns** |

NATIONAL ACADEMIES Sciences Engineering Medicine

*Family Caregiving for People with Cancer and Other Serious Illnesses: A Workshop*

**Planning Committee Roster**

**Grace Campbell, PhD, MSW, RN (Co-Chair)**
Assistant Professor, School of Nursing
Duquesne University
Adjunct Professor,
Hillman Cancer Center
University of Pittsburgh School of Medicine

**Randall A. Oyer, MD, FACC (Co-Chair)**
Clinical Professor of Medicine
Perelman School of Medicine
Executive Medical Director
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Penn Medicine Lancaster General Health

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**Allison J. Applebaum, PhD**
Associate Attending Psychologist
Director of the Caregivers Clinic
Memorial Sloan Kettering Cancer Center
Assistant Professor of Psychology in Psychiatry
Weill Cornell Medicine

**Jennifer Moore Ballentine, MA**
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Deputy Director
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**Julie Bynum, MD, MPH**
Margaret Terpenning Professor of Medicine in the Division of Geriatric Medicine
Research Professor in the Institute of Gerontology and Research
University of Michigan

**Jane Carmody, DNP, MBA, RN**
Senior Program Officer
The John A. Hartford Foundation

**Sara Damiano, LCSW, ACHP-SW**
National Director of Palliative Care
Ascension

**Pamela S. Hinds, PhD, RN, FAAN**
Executive Director, Department of Nursing Science, Professional Practice & Quality
Research Integrity Officer,
Children's National Hospital
Professor of Pediatrics, School of Medicine and Health Sciences, George Washington University

**Randy A. Jones, PhD, RN, FAAN**
Professor and Associate Dean
Partner Development and Engagement
University of Virginia School of Nursing
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Assistant Director
Alameda County Care Alliance

NATIONAL ACADEMIES Sciences Engineering Medicine

*Family Caregiving for People with Cancer and Other Serious Illnesses: A Workshop*

## Speakers and Moderators

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Vice President, Patient Experience and Program Evaluation
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US Department of Agriculture

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UPMC Magee

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Indian Health Service

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Director, GynOnc Family CARE Center
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**Alexandra Drane**
Co-Founder and CEO
ARCHANGELS

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Assistant Professor
NHCGNE Distinguished Educator in Gerontological Nursing
Nell Hodgson Woodruff School of Nursing
Emory University
Founder, Alter

**Terri Fried, MD**
Professor of Medicine, Section Chief, Geriatric Medicine
Yale University School of Medicine

**Peter Gee, MPP**
Family Caregiver
Nursing student, NYU School of Nursing

**Pamela S. Hinds, PhD, RN, FAAN**
Executive Director, Department of Nursing Science
Professional Practice & Quality Research Integrity Officer, Children's National Hospital
Professor of Pediatrics, School of Medicine and Health Sciences
George Washington University

**Lyn-Tise Jones, MA**
Family Caregiver and Care Navigator

**Randy A. Jones, PhD, RN, FAAN**
Professor and Associate Dean
Partner Development and Engagement
University of Virginia School of Nursing
Assistant Director of Outreach, Recruitment, and Engagement
University of Virginia Comprehensive Cancer Center

**Jason Karlawish, MD**
Senior Fellow, Leonard Davis Institute of Health Economics
Professor of Medicine, Perelman School of Medicine
Co-director, Penn Memory Center
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**Devin Plote, PhD**
Clinical Policy Analyst, Clinical Innovation
America's Health Insurance Plans

**Michael Reese-Wittke, MPA**
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Behavioral Health, Aging and Disability
National Academy of State Health Policy

**Courtney Harold Van Houtven, PhD, MSc**
Research Career Scientist,
Center of Innovation to Accelerate Discovery and Practice Transformation (ADAPT),
Durham Veterans Affairs Health Care System
Professor, Department of Population Health Science, Duke University School of Medicine and Duke-Margolis Center for Health Policy

**Jennifer L. Wolff, PhD**
Eugene and Mildred Lipitz Professor
Director, Roger C. Lipitz Center for Integrated Health Care
Department of Health Policy and Management
Johns Hopkins Bloomberg School of Public Health

# Roundtable on
# Quality Care for People with Serious Illness

The National Academies of Sciences, Engineering, and Medicine's Roundtable on Quality Care for People with Serious Illness fosters ongoing dialogue about improving care for people of all ages facing all stages of serious illness. To that end, the Roundtable's work and activities focus on five priority areas:

- delivery of person-centered, family-oriented care,
- communication and advance care planning,
- professional education and development,
- policies and payment systems, and
- public education and engagement

**The Roundtable on Quality Care for People with Serious Illness** convenes a diverse group of key public and private stakeholders, and sponsors public workshops to explore critical topics. Membership includes patient advocates, health care professional organizations, health care providers and insurers, foundations, federal agencies, researchers, and others interested in improving care for people with serious illness.

The Roundtable serves a critical role by:

- raising the visibility of key issues on a national stage,
- influencing policies and programs,
- fostering relationships and collaboration, and
- inspiring new ideas and shaping the field.

# PUBLIC WORKSHOPS

### Family Caregiving for People with Cancer and Other Serious Illnesses

**May 16-17, 2022**

The Roundtable on Quality Care for People with Serious Illness, The National Cancer Policy Forum and the Forum on Aging, Disability and Independence will host a collaborative workshop that will examine opportunities to better support family caregiving for people with cancer or other serious illnesses.

### Caring for People with Serious Illness during the COVID-19 Pandemic: A Workshop on Lessons Learned and Future Directions

**November 8, 18, and 30, 2021**

The COVID-19 pandemic has illuminated and exacerbated challenges in caring for people of all ages with serious illness. The workshop explored various aspects of the impact of the pandemic through the lens of serious illness care, and took place over three webinars. The first webinar focused on the impact and early responses to the pandemic, the second webinar focused on workforce and telehealth, and the final webinar focused on lessons learned for the future.

### Integrating Serious Illness Care into Primary Care Delivery

**June 10 and 17, 2021**

This workshop explored approaches to building a bridge between primary care and palliative care to improve care for people with serious illness across all care settings. The critical importance of the interdisciplinary care team was examined, as was the intersection between the principles of primary care and palliative care. Speakers also focused on key payment mechanisms and policies to support the integration of serious illness care into primary care settings.

### Advance Care Planning: Challenges and Opportunities

**October 26 and November 2, 2020**

This workshop highlighted the complexity of advance care planning (ACP). Workshop speakers explored the historical background, evolution, and different perspectives on ACP, and discussed the evidence base regarding the impact of ACP on a range of outcomes. Speakers explored the distinction between ACP and "just-in-time" or "in the moment" conversations. Workshop speakers also addressed issues such as whether the current approach to ACP is appropriate, and what changes might be considered to ensure that ACP has a greater impact on quality of care for patients with serious illness, their caregivers and families.

### Building the Workforce We Need to Care for People with Serious Illness

**November 7, 2019**

This workshop examined a key challenge in providing high-quality care to people of all ages facing serious illness: developing and supporting an adequate supply of care team members, as well as ensuring that all team members acquire and maintain appropriate training and competen-cies. The workshop addressed challenges and opportuni-ties related to educating, training, and retaining the full spectrum of the workforce for serious illness care.

### Improving Access to and Equity of Care for People with Serious Illness

**April 4, 2019**

This workshop explored challenges and opportunities to expand access and advance health equity in care for people with serious illness. Speakers discussed strategies and ap-proaches to address health disparities and barriers to care from the patient, clinician, organizational, community, and policy perspectives.

# PUBLIC WORKSHOPS

## Pain and Symptom Management for People with Serious Illness in the Context of the Opioid Epidemic

**November 29, 2018**

This workshop focused on effective approaches to address-ing the pain management needs of people with serious ill-ness in the context of the opioid misuse epidemic. Work-shop speakers discussed the unintended consequences of regulatory and legislative actions to address the opioid mis-use epidemic on patients, families and clinicians.

## Integrating Health Care and Social Services for People with Serious Illness

**July 19, 2018**

This workshop examined the range of services necessary to provide high-quality care for people facing serious illness, the strengths and limitations of existing models of integrat-ed services delivery, the role of family caregivers in pro-viding social services and supports, and identified gaps in research regarding the integration of health care and social services for people with serious illness.

## Implementing Quality Measures for Accountability in Community-based Care for People with Serious Illness

**April 17, 2018**

This workshop explored approaches to implementing quality measures for accountability purposes in community-based care programs for people with serious illness. Presentations focused on the implementation of quality measures from the perspective of patients and caregivers, health care providers and private and public sector health plans. Speakers also discussed the future use of quality measures for accreditation to support accountability for high-quality serious illness care.

## Financing and Payment Strategies to Support High-Quality Care for People with Serious Illness

**November 29, 2017**

The workshop examined innovative payment approaches to support high-quality care for people with serious illness across a range of fee-for-service, value-based, and global budgeting arrangements. Presenters discussed the chal-lenges and barriers to innovative strategies and explored potential policy approaches to address them.

## Models and Strategies to Integrate Palliative Care Principles into Serious Illness Care

**April 27, 2017**

The workshop highlighted innovative models of community-based care for people of all ages facing serious illness. Presenters and panel discussions explored community-based palliative care, pediatric palliative care, concurrent care, and the challenges and opportunities to scale and spread successful palliative care models and programs.

## Integrating the Patient and Caregiver Voice into Serious Illness Care

**December 15, 2016**

The workshop explored ways to identify and integrate the voices of seriously ill patients of all ages and their caregiv-ers into person-centered care throughout the continuum of care. Presenters shared personal perspectives and expe-riences about priorities and values important to patients and families coping with serious illness, and approaches that support integration of these priorities and values into practice.

# ROUNDTABLE MEMBERSHIP

**Peggy Maguire, JD (Co-Chair)**
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**James A. Tulsky, MD (Co-Chair)**
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Harvard Medical School

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**Susan Elizabeth Wang, MD**
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**Kaiser Permanente**

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**National Palliative Care Research Center**

**National Patient Advocate Foundation**

**New York Academy of Medicine**

**Patient-Centered Outcomes Research Institute (PCORI)**

**Social Work Hospice and Palliative Care Network**

**University of Southern California, Leonard D. Schaeffer Center for Health Policy & Economics**

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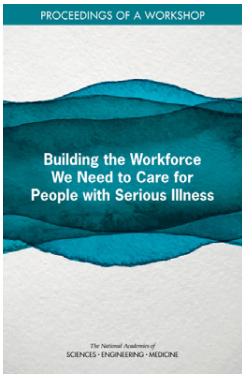
# ROUNDTABLE PUBLICATIONS


## The Challenges and Opportunities of Advance Care Planning: Proceedings of a Workshop

**https://www.nap.edu/26119**

- *Released:* April 2021
- *Downloaded*: 951 times, top 39% of all NAP publications
- *Reach:* 64 countries and 48 states and D.C.
- *Download domains:* 12% local, state, federal, and military agencies (.org, .gov., .mil); 15% academia (.edu), 72% public at large




## Building the Workforce We Need to Care for People with Serious Illness: Proceedings of a Workshop

**http://bit.ly/SeriousIllnessWorkforce**

- *Released:* May 2020
- *Downloaded* 1,451 times, top 28% of all NAP products
- *Reach:* 78 countries and 50 states and D.C.
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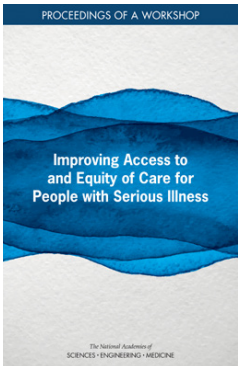


## Improving Access to and Equity of Care for People with Serious Illness: Proceedings of a Workshop

**http://bit.ly/SeriousIllnessHealthEquity**

- *Released:* September 2019
- *Downloaded* 2,364 times, top 17% of all NAP products
- *Reach:* 97 countries and 47 states and D.C.
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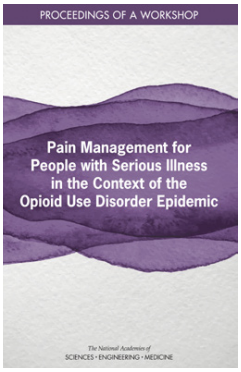


## Pain Management for People with Serious Illness in the Context of the Opioid Use Disorder Epidemic: Proceedings of a Workshop

**http://bit.ly/PainandSeriousIllness**

- *Released:* May 2019
- *Downloaded* 4,397 times, top 7% of all NAP products
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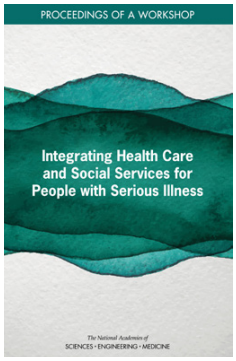


## Integrating Health Care and Social Services for People with Serious Illness: Proceedings of a Workshop

**http://bit.ly/HealthCareSocialServices**

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- *Downloaded* 3,245 times, top 11% of all NAP products
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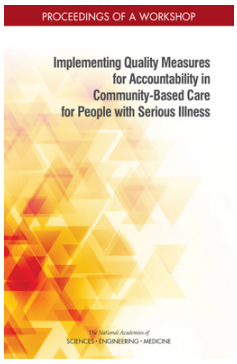


## Implementing Quality Measures for Accountability in Community-Based Care for People with Serious Illness: Proceedings of a Workshop

**http://bit.ly/QualityMeasures**

- *Released:* October 2018
- *Downloaded* 3,013 times, top 13% of all NAP products
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## Financing and Payment Strategies to Support High-Quality Care for People with Serious Illness: Proceedings of a Workshop

**http://bit.ly/FinancingStrategies**

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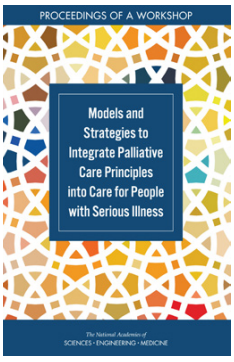


## Models and Strategies to Integrate Palliative Care Principles into Care for People with Serious Illness: Proceedings of a Workshop

**http://bit.ly/PalliativeCarePrinciples**

- *Released:* October 2017
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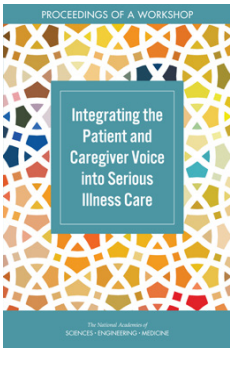


## Integrating the Patient and Caregiver Voice into Serious Illness Care: Proceedings of a Workshop

**http://bit.ly/PatientCaregiverVoice**

- *Released:* July 2017
- *Downloaded* 2,591 times, top 15% of all NAP products
- *Reach:* 93 countries and 49 states and D.C.
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# COVID-19 RELATED WEBINARS

### Social Isolation and Loneliness at the End of Life in the Era of COVID-19

**December 8, 2021**

This webinar explored topics on social isolation and loneliness during the COVID-19 pandemic and at the end of life.
*Attendees: 446; Additional Views:* TBD

### Caring for People with Serious Illness in the Home: Lessons from the COVID-19 Pandemic

**February 16, 2021**

This webinar featured a discussion that explored a range of issues including: providing palliative care and hospice care in the home, strategies to reach people with serious illness living in rural communities, including challenges and opportunities for telehealth, policy considerations and integrated care delivery models to effectively deploy vital health care resources.
*Attendees: 428; Additional Views: 261*

### Serious Illness Care, Structural Racism and Health Disparities in the Era of COVID-19

**January 29, 2021**

This webinar featured a discussion among members of the interdisciplinary care team sharing their individual perspectives and reflecting on their front-line experiences caring for seriously ill people during the COVID-19 pandemic including lessons learned, long-term strategies to mitigate suffering for marginalized populations in the future, effective approaches to build community trust in the health care system, the role of clinical training in addressing health disparities, and models to help ensure access to care and equity for all people facing serious illness.
*Attendees: 388; Additional Views: 462*

### Best Practices for Patient-Clinician Communication for People with Disabilities in the Era of COVID-19

**June 19, 2020**

This webinar showcased an overview of key patient-clinician communication challenges and disability law and policies applicable for accessible and effective communication during the COVID-19 pandemic, identified techniques to facilitate health care communication with people with disabilities, and provided tools and resources to consider for better communication in the COVID world.
*Attendees: 900; Additional Views: 376*

### Innovative Hospital-based Palliative Care Responses to the COVID-19 Pandemic: Perspectives from Program Leaders of Two Large Hospitals

**June 5, 2020**

This webinar featured the key principles and lessons learned from two specific innovative and rapid hospital-based responses (the Brookdale Department of Geriatrics and Palliative Medicine and the palliative care team at Brigham and Women's Hospital) to addressing palliative care needs during the pandemic.
*Attendees: 250; Additional Views: 119*

### Keeping Nursing Home Residents and Staff Safe in the Era of COVID-19: Effective Testing and Cohorting to Minimize Risk of Transmission

**June 2, 2020**

This webinar explored the challenges to effective cohorting of nursing home residents during the COVID-19 outbreak to prevent virus transmission, discuss the design and implementation of an actionable cohorting strategy based on CDC guidance, examine approaches to mitigate risk associated with new admissions, re-admissions, and residents who must routinely leave the nursing home or long-term care facility for medical appointments.
*Attendees: 285; Additional Views: 128*

### Keeping Nursing Home Residents and Staff Safe in the Era of COVID-19

**April 22, 2020**

This webinar highlighted the innovative approaches to address these complex challenges that are currently being implemented in the state of Maryland including approaches from health care professionals at Johns Hopkins University School of Medicine, the state department of health, emergency medicine professionals, and “strike teams” made up of members of the National Guard.
*Attendees: 1600; Additional Views: 901*

# OTHER ROUNDTABLE PUBLICATIONS

### The Road to Readiness: Guiding Families of Children and Adolescents with Serious Illness Toward Meaningful Advance Care Planning Discussions

**https://nam.edu/the-road-to-readiness/**

**Authors:** Lori Wiener, Cynthia Bell, Jessica Spruit, Meaghann S. Weaver, and Amanda L. Thompson

**Released:** August 2, 2021

### Serious Illness Care And The Opioid Epidemic: Reflections On A NASEM Workshop

**https://www.healthaffairs.org/do/10.1377/hblog20190605.155057/full/**

**Authors:** Jessica Merlin, Andrew Dreyfus, and James A. Tulsky

**Released:** June 7, 2019

### Community-Based Models of Care Delivery for People with Serious Illness

**https://nam.edu/community-based-models-of-care-delivery-for-people-with-serious-illness/**

**Authors:** Jeffrey Cohn, Janet Corrigan, Joanne Lynn, Diane Meier, Jeri Miller, Joseph Shega, and Susan Wang

**Released:** April 13, 2017

NATIONAL ACADEMIES Sciences Engineering Medicine

**UPCOMING WORKSHOP**

**SAVE THE DATE: NOVEMBER 7, 2022**

# ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

*Supporting and Sustaining the Current and Future Workforce to Care for People with Serious Illness*

## Statement of Task

A planning committee of the National Academies of Sciences, Engineering, and Medicine will organize and conduct a public workshop to explore issues related to supporting and sustaining the workforce to care for people with serious illness. This workforce is interdisciplinary in nature and includes palliative care providers, nurses, social workers, community health workers and chaplains. The workshop will feature invited presentations and discussions that may explore topics such as:

- Impact of the pandemic on the workforce caring for people with serious illness
  - Exacerbation of existing workforce shortages by the "great resignation"
  - Effect of emotional stress, moral distress, post-traumatic stress disorder
- Importance of leadership, partnerships and care delivery models (such as palliative care)
  - Roles for institutions, organizations, mentors and trainers in developing and supporting the workforce of the future
  - Developing effective partnerships with primary care and community health workers for serious illness care
  - Ways to improve the care system to support clinician well-being
  - Models of care delivery that help support the well-being of all members of the interdisciplinary team caring for people with serious illness
- Ways in which health care institutions and organizations, educational organizations, professional societies and associations and other health care partners can advance diversity, equity and inclusion within the workforce caring for people with serious illness

The planning committee will organize the workshop, select and invite speakers and discussants, and moderate the discussions. A proceedings of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

**November 7, 2022**

**Keck Center of the National Academies**
**500 Fifth Street, NW, Washington, DC**

NATIONAL ACADEMIES Sciences Engineering Medicine

## ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

## SPONSORS

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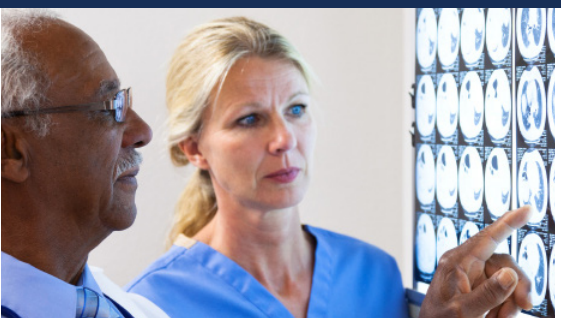
- National Patient Advocate Foundation
- New York Academy of Medicine
- Patient-Centered Outcomes Research Institute (PCORI)
- USC Leonard D. Schaeffer Center for Health Policy & Economics

NATIONAL CANCER POLICY FORUM

# ABOUT THE FORUM



The National Cancer Policy Forum serves as a trusted venue in which experts can identify emerging high-priority policy issues in cancer research and cancer care and work collaboratively to examine those issues through convening activities focused on opportunities for action. The Forum provides a continual focus within the National Academies on cancer, addressing issues in science, clinical medicine, public health, and public policy that are relevant to the goal of reducing the cancer burden, through prevention and by improving the care and outcomes for those diagnosed with cancer. Forum activities inform the cancer community and the public about critical policy issues through workshops and published reports. The Forum has members with a broad range of expertise in cancer, including patient advocates, clinicians, and basic, translational, and clinical scientists. Members represent patients, federal agencies, academia, professional organizations, nonprofits, and industry.

The Forum has addressed a wide array of topics, including:

- enhancing collaborations to accelerate research and development;
- improving the quality and value of care for patients who have been diagnosed with or are at risk for cancer;
- developing tools and technologies to enhance cancer research and care; and
- examining factors that influence cancer incidence, mortality, and disparities.

nationalacademies.org/NCPF

#NatlCancerForum

To receive updates on the National Cancer Policy Forum, visit **nationalacademies.org/NCPF**

NATIONAL ACADEMIES Sciences Engineering Medicine

# Upcoming and Recent Workshops

## Addressing Resistance in the Development of Cancer Immune Modulator Therapeutics

**November 14-15, 2022**

Single agent immune modulating therapies hold great promise for cancer treatment. This workshop will consider the current challenges related to resistance to immune modulator therapies and discuss potential policy levers that could help to overcome these challenges. The workshop will feature presentations and discussions on topics such as:

- An overview of the unique types of immunotherapy resistance based on the causes of resistance, and gaps in current understanding.
- Policy challenges and opportunities to address the problem of resistance, including:
  - Criteria to move single agents into clinical trials, criteria to use single agents in combination therapy development, as well as criteria to assess cancer immunotherapy combinations in early-phase clinical trials.
  - The roles of preclinical modeling and clinical and predictive biomarkers (e.g., companion diagnostics, in vivo imaging) for assessing safety and efficacy.
  - The types of clinical trial designs needed for regulatory approval.
  - Use of big data to aid in determining the dominant drivers of cancer immunotherapy resistance and to predict immunotherapy responses.

Workshop website in development

## Advancing Progress in Cancer Prevention and Risk Reduction

**June 27-28, 2022**

This workshop will consider the current state of knowledge on risk factors for cancer and best practices for cancer prevention and risk recuction. Workshop sessions will focus on:

- An Overview of the Evidence Base on Risk Factors for Cancer
- Implementing Population-Based Cancer Prevention Strategies
- Innovative Strategies for Population-Based Cancer Prevention
- Implementing Clinic-Based Cancer Prevention Strategies
- Innovative Strategies for Clinic-Based Cancer Prevention
- Communicating about Cancer Risk and Prevention
- Opportunities to Spur Progress in Cancer Prevention and Risk Reduction

Workshop website

## Family Caregiving for People With Cancer and Other Serious Illnesses

**Collaborative workshop convened by:**
National Cancer Policy Forum
Roundtable on Quality Care for People with Serious Illness
Forum on Aging, Disability, and Independence

**May 16-17, 2022**

This workshop will use cancer as a lens to examine issues that affect family caregivers for people with serious illnesses. Presentations and discussions will include: strategies to better capture, understand, and act on family caregiver input and experience to improve patient care and to support family caregivers; research and policy opportunities to better support family caregiving; and strategies to better embed a health equity focus in family caregiving research, policy and practice.

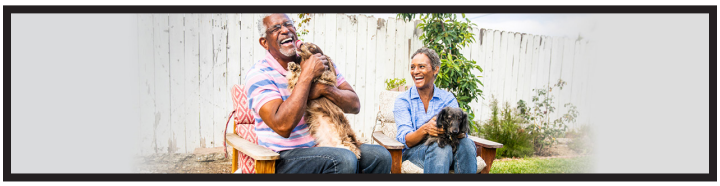
Workshop website

## Innovation in Electronic Health Records for Oncology Care, Research, and Surveillance

**February 28-March 1, 2022**

Electronic health records (EHRs) affect clinician and practice safety and efficiency, the quality of care, patient satisfaction, and data acquisition. This workshop, convened by the Forum in collaboration with the Computer Science and Telecommunications Board, examined potential opportunities to improve patient care and outcomes, as well as strategies to enhance innovation and to promote health equity in the development, implementation, and use of EHRs in oncology care, research, and surveillance.

Workshop videos and presentations



## The Role of Companion Animals as Sentinels for Predicting Environmental Exposure Effects on Aging and Cancer Susceptibility in Humans

**December 1-3, 2021**

Companion animals have a potential role as sentinels of relevant, shared environmental exposures that may affect human aging and cancer. This workshop examined the opportunities and challenges for using this novel translational approach to exposure science as a way to accelerate the knowledge turn in this evolving field.

Workshop videos and presentations
Poster session
Proceedings

# Recent Workshops

## Promoting Health Equity in Cancer Care

**October 25-26, 2021**

Significant advancements in the delivery of high-quality cancer care and improvements in patient outcomes have been achieved in recent years; however, such progress has not been evenly distributed across the U.S. population. The Forum, in collaboration with the Roundtable on the Promotion of Health Equity, convened a workshop to examine opportunities to improve health equity for patients with cancer.

Workshop videos and presentations

### *Webinar Series: Addressing Social Needs in Cancer Care*

In advance of the workshop, *Promoting Health Equity in Cancer Care,* the Forum convened a webinar series focusing on opportunities to better assess and address the social needs of patients with cancer.

- May 10, 2021: Food Insecurity among Patients with Cancer
- August 9, 2021: Housing Insecurity among Patients with Cancer
- September 21, 2021: Transportation Needs among Patients with Cancer

## Innovation in Cancer Care and Cancer Research in the Context of the COVID-19 Pandemic

**July 26-27, 2021**

The COVID-19 pandemic has led to dramatic adjustments in cancer care delivery and cancer research. This workshop examined these changes, and considered lessons learned in order to improve the delivery of high-quality cancer care and the conduct of cancer clinical trials in the post-pandemic era. Participants identified potential policy opportunities to retain and build on the beneficial changes that occurred during the pandemic.

Workshop videos and presentations
Proceedings

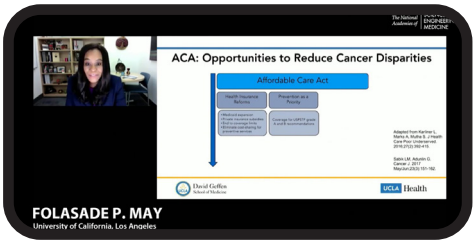
## Impact of the Affordable Care Act on Cancer Prevention and Cancer Care

**March 1-2, 2021**

The Forum convened this workshop to examine the evidence base on how the Patient Protection and Affordable Care Act (ACA) has altered the landscape of cancer prevention and care delivery. Workshop presentations and discussions reviewed the effects of the ACA on people at risk for or living with cancer and provided insight into remaining policy challenges that could inform future efforts to improve the delivery of high-quality cancer care across the care continuum.

Workshop videos and presentations
Proceedings
Reels
Interactive overview


**Still from the workshop reel: Opportunties for Action: Strengthening Patient, Clinician, and Community Engagement**




**Still from the workshop reel: Improving Access to High-Quality Prevention and Care**

**S**


**Still from the workshop reel: Addressing the Social Determinants of Health to Address Health Equity**

## Addressing the Adverse Consequences of Cancer Treatment

**November 9-10, 2020**

Cancer treatment can lead to an array of significant short- and long-term physical, mental, and socioeconomic consequences for patients and their families. The Forum, in collaboration with the Forum on Aging, Disability, and Independence, convened this workshop to examine opportunities to prevent and mitigate the adverse effects of cancer treatment and improve quality of life for cancer survivors and their families.

Workshop videos and presentations
Proceedings

## Opportunities and Challenges for Using Digital Health Applications in Oncology

**July 13-14, 2020**

The Forum, in collaboration with the Forum on Cyber Resilience, convened a workshop to examine the role of digital health applications in oncology research and care. Workshop speakers discussed topics such as exemplars of novel digital health applications; regulatory priorities; ethical, security, governance, and payment considerations; and opportunities to improve data availability and use in EHRs and large databases.

Workshop videos and presentations
Proceedings

## FORUM SPONSORS

- Centers for Disease Control and Prevention
- National Institutes of Health/National Cancer Institute
- American Association for Cancer Research
- American Cancer Society
- American College of Radiology
- American Society of Clinical Oncology
- Association of American Cancer Institutes
- Association of Community Cancer Centers
- Bristol-Myers Squibb
- Cancer Support Community
- Flatiron Health
- Merck
- National Comprehensive Cancer Network
- National Patient Advocate Foundation
- Novartis Oncology
- Oncology Nursing Society
- Pfizer Inc.
- Sanofi
- Society for Immunotherapy of Cancer

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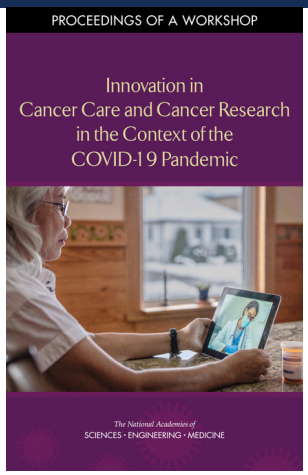
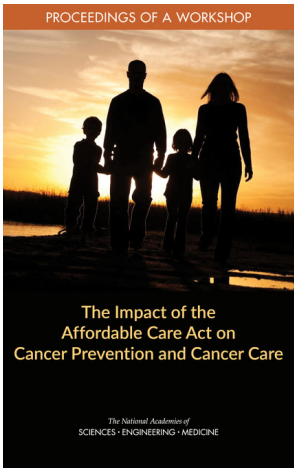
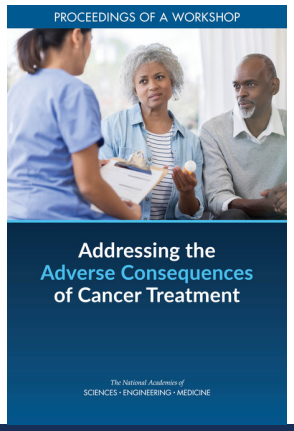
# NATIONAL CANCER POLICY FORUM

# WORKSHOP PROCEEDINGS AND RELATED PUBLICATIONS




## WORKSHOP PROCEEDINGS

### 2022

Innovation in Electronic Health Records for Cancer Care, Research, and Surveillance: A Workshop (In Process)

Promoting Health Equity in Cancer Care: Proceedings of a Workshop (In Process)

The Role of Companion Animals as Sentinels for Predicting Environmental Exposure Effects on Aging and Cancer Susceptibility in Humans: Proceedings of a Workshop

Innovation in Cancer Care and Cancer Research in the Context of the COVID-19 Pandemic: Proceedings of a Workshop

Impact of the Affordable Care Act on Cancer Prevention and Cancer Care: Proceedings of a Workshop

### 2021

Addressing the Adverse Consequences of Cancer Treatment: Proceedings of a Workshop

Opportunities and Challenges for Using Digital Health Applications in Oncology: Proceedings of a Workshop

Improving the Evidence Base for Treatment Decision Making for Older Adults with Cancer: Proceedings of a Workshop— in Brief

Advancing Progress in the Development and Implementation of Effective, High-Quality Cancer Screening: Proceedings of a Workshop

Drug Research and Development for Adults Across the Older Age Span: Proceedings of a Workshop

### 2020

Reflections on Sharing Clinical Trial Data: Challenges and a Way Forward: Proceedings of a Workshop

Applying Big Data to Address the Social Determinants of Health in Oncology: Proceedings of a Workshop

Health Literacy and Communication Strategies in Oncology: Proceedings of a Workshop

Enhancing Scientific Reproducibility in Biomedical Research Through Transparent Reporting: Proceedings of a Workshop

### 2019

Developing and Sustaining an Effective and Resilient Oncology Careforce: Proceedings of a Workshop

Advancing Progress in the Development of Combination Cancer Therapies with Immune Checkpoint Inhibitors: Proceedings of a Workshop

Improving Cancer Diagnosis and Care: Clinical Application of Computational Methods in Precision Oncology: Proceedings of a Workshop

To receive updates on the National Cancer Policy Forum, visit:

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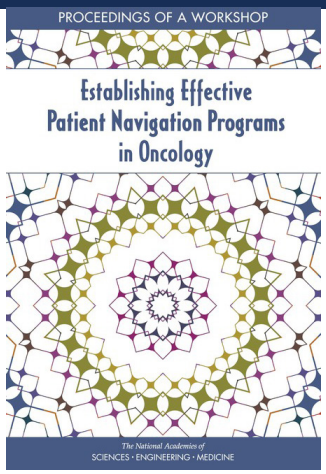
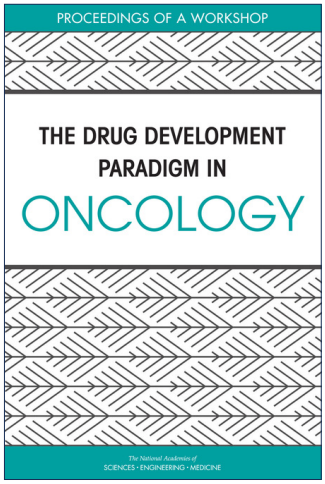
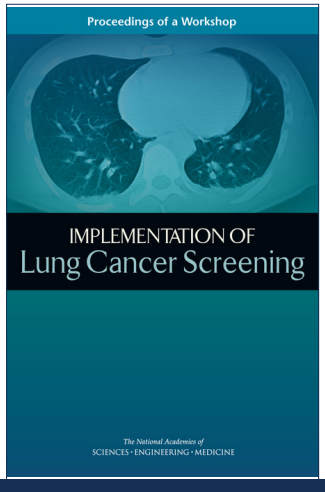







# WORKSHOP PROCEEDINGS

## 2018

Improving Cancer Diagnosis and Care: Patient Access to Oncologic Imaging and Pathology Expertise and Technologies: Proceedings of a Workshop

Establishing Effective Patient Navigation Programs in Oncology: Proceedings of a Workshop

Long-Term Survivorship Care After Cancer Treatment: Proceedings of a Workshop

## 2017

The Drug Development Paradigm in Oncology: Proceedings of a Workshop

Cancer Care in Low-Resource Areas: Cancer Treatment, Palliative Care, and Survivorship Care: Proceedings of a Workshop

Implementation of Lung Cancer Screening: Proceedings of a Workshop

Incorporating Weight Management and Physical Activity Throughout the Cancer Care Continuum: Proceedings of a Workshop

## 2016

Policy Issues in the Clinical Development and Use of Immunotherapy for Cancer Treatment: Proceedings of a Workshop

Cancer Care in Low-Resource Areas: Cancer Prevention and Early Detection: Workshop Summary

Appropriate Use of Advanced Technologies for Radiation Therapy and Surgery in Oncology: Workshop Summary

## 2015

Comprehensive Cancer Care for Children and Their Families: Summary of a Joint Workshop by the Institute of Medicine and the American Cancer Society

Policy Issues in the Development and Adoption of Biomarkers for Molecularly Targeted Cancer Therapies: Workshop Summary

Assessing and Improving the Interpretation of Breast Images: Workshop Summary

Role of Clinical Studies for Pets with Naturally Occurring Tumors in Translational Cancer Research: Workshop Summary

## 2014

Ensuring Patient Access to Affordable Cancer Drugs: Workshop Summary

Contemporary Issues for Protecting Patients in Cancer Research: Workshop Summary

## 2013

Identifying and Addressing the Needs of Adolescents and Young Adults with Cancer: Workshop Summary

Implementing a National Cancer Clinical Trials System for the 21st Century: Second Workshop Summary

Sharing Clinical Research Data: Workshop Summary

Delivering Affordable Cancer Care in the 21st Century: Workshop Summary

Reducing Tobacco-Related Cancer Incidence and Mortality: Workshop Summary

## 2012

The Role of Obesity in Cancer Survival and Recurrence: Workshop Summary

Informatics Needs and Challenges in Cancer Research: Workshop Summary

Facilitating Collaborations to Develop Combination Investigational Cancer Therapies: Workshop Summary

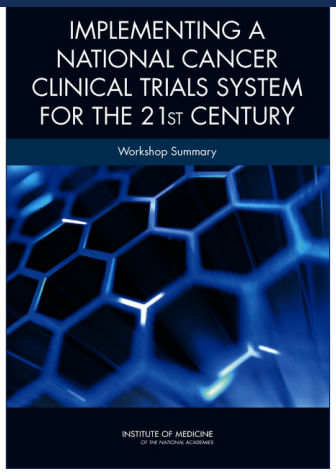
## 2011

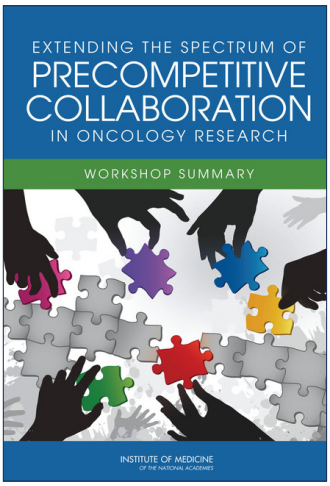
Implementing a National Cancer Clinical Trials System for the 21st Century: Workshop Summary

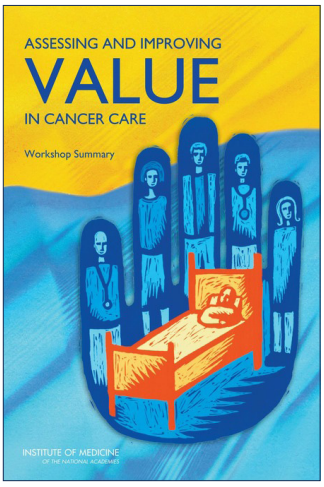
Patient-Centered Cancer Treatment Planning: Improving the Quality of Oncology Care: Workshop Summary

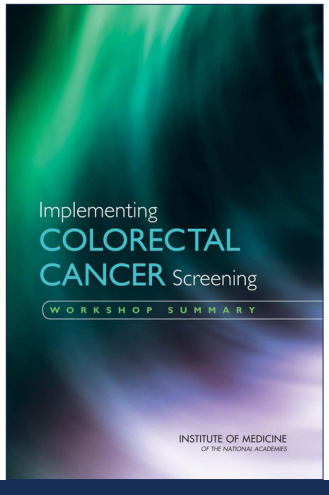
The National Cancer Policy Summit: Opportunities and Challenges in Cancer Research and Care

Nanotechnology and Oncology: Workshop Summary




# WORKSHOP PROCEEDINGS

## 2011, continued

Implementing a National Cancer Clinical Trials System for the 21st Century: Workshop Summary
Patient-Centered Cancer Treatment Planning: Improving the Quality of Oncology Care: Workshop Summary
The National Cancer Policy Summit: Opportunities and Challenges in Cancer Research and Care
Nanotechnology and Oncology: Workshop Summary

## 2010

Genetic Testing (with the National Research Council): Summary of a Workshop
Extending the Spectrum of Precompetitive Collaboration in Oncology Research: Workshop Summary
A Foundation for Evidence-Driven Practice: A Rapid Learning System for Cancer Care: Workshop Summary
Policy Issues in the Development of Personalized Medicine in Oncology: Workshop Summary

## 2009

Assessing and Improving Value in Cancer Care: Workshop Summary
Ensuring Quality Cancer Care Through the Oncology Workforce: Sustaining Care in the 21st Century: Workshop Summary
Multi-Center Phase III Clinical Trials and the NCI Cooperative Group Program: Workshop Summary

## 2008

Implementing Colorectal Cancer Screening: Workshop Summary
Improving the Quality of Cancer Clinical Trials: Workshop Summary

## 2007

Cancer-Related Genetic Testing and Counseling: Workshop Proceedings
Cancer in Elderly People: Workshop Proceedings
Implementing Cancer Survivorship Care Planning: Workshop Summary

## 2006

Effect of the HIPAA Privacy Rule on Health Research: Proceedings of a Workshop
Developing Biomarker-Based Tools for Cancer Screening, Diagnosis, and Treatment: Workshop Summary

# RELATED WORK

## CONSENSUS STUDY REPORTS BUILDING ON NCPF WORK

Childhood Cancer and Functional Impacts Across the Care Continuum (2021)
Report: nap.edu/catalog/25944

Diagnosing and Treating Adult Cancers and Associated Impairments (2021)
Report: nap.edu/catalog/25956

Guiding Cancer Control: A Path to Transformation (2019)
Report: nap.edu/catalog/25438

Making Medicines Affordable: A National Imperative (2017)
Report: nap.edu/catalog/24946

Biomarker Tests for Molecularly Targeted Therapies: Key to Unlocking Precision Medicine (2016)
Report: nap.edu/catalog/21860

Ovarian Cancers: Evolving Paradigms in Research and Care (2016)
Report: nap.edu/catalog/21841

Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis (2013)
Report: nap.edu/catalog/18359

Evolution of Translational Omics: Lessons Learned and the Path Forward (2012)
Report: nap.edu/catalog/13297

A National Cancer Clinical Trials System for the 21st Century: Reinvigorating the NCI Cooperative Group Program (2010)
Report: nap.edu/catalog/12879

Evaluation of Biomarkers and Surrogate Endpoints in Chronic Disease (2010)
Report: nap.edu/catalog/12869

Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research (2009)
Report: nap.edu/catalog/12458

Cancer Biomarkers: The Promises and Challenges of Improving Detection and Treatment (2007)
Report: nap.edu/read/11892

## INDIVIDUALLY AUTHORED PUBLICATIONS BUILDING ON NCPF WORK

Independent, individually authored articles arising from NCPF workshops—and consensus studies building on NCPF work—include:

### 2022

- Nekhlyudov L., G.B. Campbell., K.H. Schmitz, G.A. Brooks, A.J. Kumar, P.A. Ganz, and D. Von Ah 2022. Cancer-related impairments and functional limitations among long-term cancer survivors: Gaps and opportunities for clinical practice. *Cancer* 128(2): 222-229. https://pubmed.ncbi.nlm.nih.gov/34529268/

### 2021

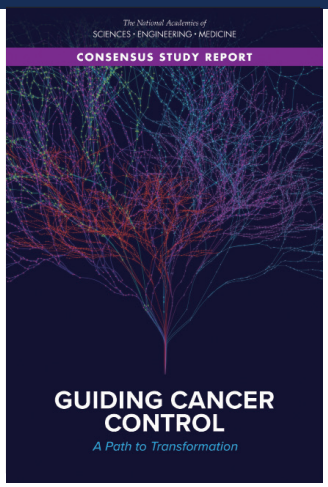
- Bertagnolli, M.M. and H. Singh. 2021. Treatment of older adults with cancer - addressing gaps in evidence. *New England Journal of Medicine* 385:1062-1065. https://www.nejm.org/doi/full/10.1056/NEJMp2106089
- Housten, A.J., C.M. Gunn, M.K. Paasche-Orlow, and K.M. Basen-Engquist. 2021. Health literacy interventions in cancer: A systematic review. *Journal of Cancer Education* 36(2):240-252. https://pubmed.ncbi.nlm.nih.gov/33155097/

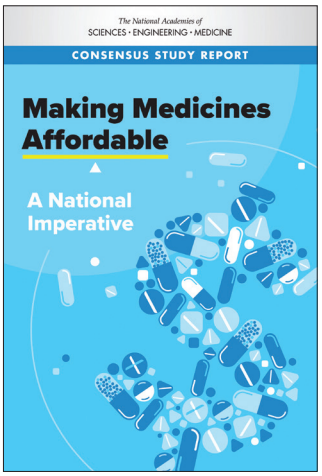
### 2020

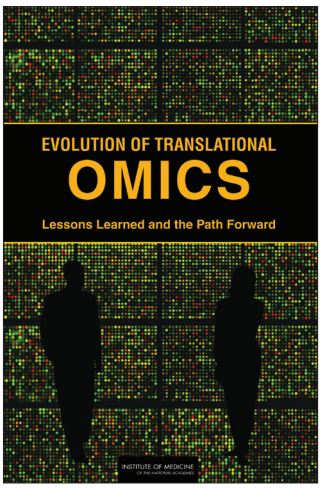
- Schilsky, R.L., S. Nass, M.M. Le Beau, and E.J. Benz, Jr. 2020. Progress in cancer research, prevention, and care. *New England Journal of Medicine* 383(10):897-990. https://www.nejm.org/doi/full/10.1056/NEJMp2007839.
- Shulman, L. N., L. K. Sheldon, and E. J. Benz. 2020. The future of cancer care in the United States—Overcoming workforce capacity limitations. *JAMA Oncology* 6(3):327-328. https://jamanetwork.com/journals/jamaoncology/article-abstract/2758839.
- Panagiotou, O. A., L. Hoffman-Högg, H. Hricak, S. N. Khleif, M. A. Levy, D. Magnus, M. J. Murphy, B. Patel, R. A. Winn, S. J. Nass, C. Gatsonis, and C. R. Cogle. 2020. Clinical application of computational methods in precision oncology: A review. *JAMA Oncology* 6(8):1282:1286. https://jamanetwork.com/journals/jamaoncology/article-abstract/2765757.

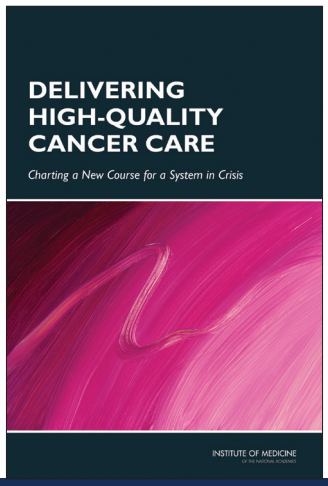
### 2019

- Balogh, E. P., A. B. Bindman, S. G. Eckhardt, S. Halabi, R. D. Harvey, I. Jaiyesimi, R. Miksad, H. L. Moses, S. J. Nass, R. L. Schilsky, S. Sun, J. M. Torrente, and K. E. Warren. 2019. Challenges and opportunities to updating prescribing information for longstanding oncology drugs. *The Oncologist* 24:1-7. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7066705/.



## 2019, continued


- Takvorian, S. U., E. Balogh, S. Nass, V. L. Valentin, L. Hoffman-Högg, R. A. Oyer, R. W. Carlson, N. J. Meropol, L. K. Sheldon, and L. N. Shulman. 2019. Developing and sustaining an effective and resilient oncology careforce: Opportunities for action, *Journal of the National Cancer Institute* 112(7):663-670. https://doi.org/10.1093/jnci/djz239
- Kline, R. M., G. B. Rocque, E. A. Rohan, K. A. Blackley, C. A. Cantril, M. L. Pratt-Chapman, H. A. Burris, and L.N Shulman. 2019. Patient navigation in cancer: The business case to support clinical needs. J*ournal of Oncology Practice* 15(11):585-590. https://www.ncbi.nlm.nih.gov/pubmed/31509483.
- Lubejko, B. G., C. Cantril, L. H. Hogg, and L. Kennedy Sheldon. 2019. Novice oncology nurse navigator: Core elements in establishing training needs and building on competencies. *Clinical Journal of Oncology Nursing* 23(4):387-394. https://www.ncbi.nlm.nih.gov/pubmed/31322621.
- Nass, S. J., M.B. Cohen, R. Nayar, M.M. Zutter, E. P. Balogh, R. L. Schilsky, H. Hricak, and K.S.J. Elenitoba-Johnson. 2019. Improving cancer diagnosis and care: Patient access to high-quality oncologic pathology. *The Oncologist* 24(10):1287-1290. https://www.ncbi.nlm.nih.gov/pubmed/31366725.
- Lopez, D., M. L. Pratt-Chapman, E. A. Rohan, L. K. Sheldon, K. Basen-Engquist, R. Kline, L. N. Shulman, and E. J. Flores. 2019. Establishing effective patient navigation programs in oncology. *Supportive Care in Cancer* 27(6):1985-1996. https://www.ncbi.nlm.nih.gov/pubmed/30887125.
- Nass, S. J., C. R. Cogle, J. A. Brink, C. P. Langlotz, E. P. Balogh, A. Muellner, D. Siegal, R. L. Schilsky, and H. Hricak. 2019. Improving cancer diagnosis and care: Patient access to oncologic imaging expertise. J*ournal of Clinical Oncology* 37(20):1690-1694. https://www.ncbi.nlm.nih.gov/pubmed/31050908.


## 2018


- Kline, R. M., N. K. Arora, C. J. Bradley, E. R. Brauer, D. L. Graves, N. Buchanan Lunsford, M. S. McCabe, S. F. Nasso, L. Nekhlyudov, J. H. Rowland, R. M. Schear, and P. A. Ganz. Long-term survivorship care after cancer treatment—summary of a 2017 National Cancer Policy Forum workshop. *Journal of the National Cancer Institute* 110(12):1300-1310. https://www.ncbi.nlm.nih.gov/pubmed/30496448.
- Nass, S. J., M. Rothenberg, R. Pentz, H. Hricak, A. Abernethy, K. Anderson, A. W. Gee, R.D. Harvey, S. Piantadosi, M. M. Bertagnolli, D. Schrag, and R. L. Schilsky. Accelerating anticancer drug development—opportunities and trade-offs. *Nature Reviews Clinical Oncology* 15(12):777-786. https://www.ncbi.nlm.nih.gov/pubmed/30275514.
- Demark-Wahnefried, W., K. H. Schmitz, C. M. Alfano, J. R. Bail, P. J. Goodwin, C. A. Thomson, D. W. Bradley, K. S. Courneya, C. A. Befort, C. S. Denlinger, J. A. Ligibel, W. H. Dietz, M. R. Stolley, M. L. Irwin, M. M. Bamman, C. M. Apovian, B. M. Pinto, K. Y. Wolin, R. M. Ballard, A. J. Dannenberg, E. G. Eakin, M. M. Longjohn, S. D. Raffa, L. L. Adams-Campbell, J. S. Buzaglo, S. J. Nass, G. M. Massetti, E. P. Balogh, E. S. Kraft, A. K. Parekh, D. M. Sanghavi, G. S. Morris, and K. Basen-Engquist. 2018. Weight management and physical activity throughout the cancer care continuum. *CA: A Cancer Journal for Clinicians* 68(1):64-89. https://www.ncbi.nlm.nih.gov/pubmed/29165798.


## 2017


- Basen-Engquist, K., C. M. Alfano, M. Maitin-Shepard, C. A. Thomson, K. H. Schmitz, B. M. Pinto, K. Stein, D. S. Zucker, K. L. Syrjala, E. Fallon, C. Doyle, and W. Demark-Wahnefried. 2017. Agenda for translating physical activity, nutrition, and weight management interventions for cancer survivors into clinical and community practice. *Obesity* (Silver Spring) 25(Suppl 2):S9-S22. https://www.ncbi.nlm.nih.gov/pubmed/29086526.
- Smith, G. L., P. A. Ganz, J. E. Bekelman, S. J. Chmura, J. J. Dignam, J. A. Efstathiou, R. Jagsi, P. A. Johnstone, M. L. Steinberg, S. B. Williams, J. B. Yu, A. L. Zietman, R. R. Weichselbaum, and Y.-C. Shih. 2017. Promoting the appropriate use of advanced radiation technologies in oncology: Summary of a National Cancer Policy Forum workshop. *International Journal of Radiation Oncology • Biology • Physics* 97(3):450-461. https://www.ncbi.nlm.nih.gov/pubmed/28011046.


## 2016


- Kirch, R., G. Reaman, C. Feudtner, L. Wiener, L. A. Schwartz, L. Sung, and J. Wolfe. 2016. Advancing a comprehensive cancer care agenda for children and their families: Institute of Medicine workshop highlights and next steps. *CA: A Cancer Journal for Clinicians* 66(5):398-407. https://www.ncbi.nlm.nih.gov/pubmed/27145249.


## 2015


- Nass, S. J., L. K. Beaupin, W. Demark-Wahnefried, K. Fasciano, P. A. Ganz, B. Hayes-Lattin, M. M. Hudson, B. Nevidjon, K. C. Oeffinger, R. Rechis, L. C. Richardson, N. L. Seibel, and A. W. Smith. 2015. Identifying and addressing the needs of adolescents and young adults with cancer: Summary of an Institute of Medicine workshop. *Oncologist* 20(2):186-195. https://www.ncbi.nlm.nih.gov/pubmed/25568146.


## 2014


- Bertagnolli, M. M., R. Canetta, and S. J. Nass. 2014. Expanding public-private collaborations to enhance cancer drug development: A Report of the Institute of Medicine's workshop series, "Implementing a National Cancer Clinical Trials System for the 21st Century." *Oncologist* 19(11):1179-1185. https://www.ncbi.nlm.nih.gov/pubmed/25326161.
- Balogh, E. P., C. Dresler, M. E. Fleury, E. R. Gritz, T. J. Kean, M. L. Myers, S. J. Nass, B. Nevidjon, B. A. Toll, G. W. Warren, and R. S. Herbst. 2014. Reducing tobacco-related cancer incidence and mortality: Summary of an Institute of Medicine workshop. *Oncologist* 19(1):21-31. https://www.ncbi.nlm.nih.gov/pubmed/24304712.
- Ferrell, B. R., T. J. Smith, L. Levit, and E. Balogh. 2014. Improving the quality of cancer care: Implications for palliative care. *Journal of Palliative Medicine* 17(4):393-399. https://www.ncbi.nlm.nih.gov/pubmed/24548217.

## 2013


- Ramsey, S. D., P. A. Ganz, V. Shankaran, J. Peppercorn, and E. Emanuel. 2013. Addressing the American health-care cost crisis: Role of the oncology community. *Journal of the National Cancer Institute* 105(23):1777-1781. https://www.ncbi.nlm.nih.gov/pubmed/24226096.
- Balogh, E. P., P. B. Bach, P. D. Eisenberg, P. A. Ganz, R. J. Green, J. C. Gruman, S. J. Nass, L. N. Newcomer, S. D. Ramsey, J. E. Schottinger, and Y. T. Shih. 2013. Practice-changing strategies to deliver affordable, high-quality cancer care: Summary of an Institute of Medicine workshop. *Journal of Oncology Practice* 9(6s):54s-59s. https://www.ncbi.nlm.nih.gov/pubmed/29431037.


## 2012


- Demark-Wahnefried, W., E. A. Platz, J. A. Ligibel, C. K. Blair, K. S. Courneya, J. A. Meyerhardt, P. A. Ganz, C. L. Rock, K. H. Schmitz, T. Wadden, E. J. Philip, B. Wolfe, S. M. Gapstur, R. Ballard-Barbash, A. McTiernan, L. Minasian, L. Nebeling, and P. J. Goodwin. 2012. The role of obesity in cancer survival and recurrence. *Cancer Epidemiology, Biomarkers & Prevention* 21(8):1244-1259. https://www.ncbi.nlm.nih.gov/pubmed/22695735.
- LoRusso, P. M., R. Canetta, J. A. Wagner, E. P. Balogh, S. J. Nass, S. A. Boerner, and J. Hohneker. 2012. Accelerating cancer therapy development: The importance of combination strategies and collaboration. Summary of an Institute of Medicine workshop. *Clinical Cancer Research* 18(22):6101-6109. https://www.ncbi.nlm.nih.gov/pubmed/23065428.


## 2011


- Nass, S. J., E. Balogh, and J. Mendelsohn. 2011. A national cancer clinical trials network: Recommendations from the Institute of Medicine. *American Journal of Therapeutics* 18(5):382-391. https://www.ncbi.nlm.nih.gov/pubmed/21326081.
- Balogh, E. P., P. A. Ganz, S. B. Murphy, S. J. Nass, B. R. Ferrell, and E. Stovall. 2011. Patient-centered cancer treatment planning: Improving the quality of oncology care. Summary of an Institute of Medicine workshop. *Oncologist* 16(12):1800-1805. https://www.ncbi.nlm.nih.gov/pubmed/22128118.


## 2010


- Altshuler, J. S., E. Balogh, A. D. Barker, S. L. Eck, S. H. Friend, G. S. Ginsburg, R. S. Herbst, S. J. Nass, C. M. Streeter, and J. A. Wagner. 2010. Opening up to precompetitive collaboration. *Science Translational Medicine* 2(52):52cm26. https://www.ncbi.nlm.nih.gov/pubmed/20926831.
- Levit, L., A.P. Smith, E.J. Benz, Jr., and B. Ferrell. 2010. Ensuring Quality Cancer Care Through the Oncology Workforce. 2010. *Journal of Oncology Practice* 6(1):7-11. https://ascopubs.org/doi/abs/10.1200/JOP.091067

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Oncology

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We are grateful for the support of our sponsors, which is crucial to the work of the Forum.

NATIONAL CANCER POLICY FORUM

## Advancing Progress in Cancer Prevention and Risk Reduction: A Workshop

**June 27-28, 2022**
Keck Center of the National Academies, Room 100
500 Fifth Street, NW
Washington, DC 20001

**Workshop website:** https://www.nationalacademies.org/event/06-27-2022/advancing-progress-in-cancer-prevention-and-risk-reduction-a-workshop

**Statement of Task:**
A planning committee will organize and host a 1.5-day public workshop that will consider the current state of knowledge regarding risk factors for cancer and strategies for interventions across multiple levels to reduce cancer risk. The workshop will feature invited presentations and panel discussions on topics that may include:

- An overview of the current evidence base for modifiable (e.g., environmental and behavioral) risk factors for cancer, including consideration of how these factors are distributed across populations and influenced by socioeconomic factors.
- Best practices and innovative approaches to implement population-based cancer prevention strategies, including the potential for collaborations with other disease prevention efforts.
- Opportunities to overcome challenges in the delivery of cancer prevention services within communities and health care settings, including consideration of specific strategies for low-resource areas.
- Opportunities to improve implementation of vaccine-based interventions for cancer prevention, as well as for pharmacological and surgical interventions to reduce cancer risk.
- Methods for assessing efficacy of programs and interventions for cancer prevention and risk reduction, including the identification and validation of biomarkers as surrogate endpoints.

The planning committee will develop the agenda for the workshop sessions, select and invite speakers and discussants, and moderate the discussions. A proceedings of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

**Provisional Planning Committee:**
Garnet L. Anderson [co-chair], Fred Hutchinson Cancer Research Center
Karen Basen-Engquist [co-chair], The University of Texas MD Anderson
Gwen Darien, National Patient Advocate Foundation
Nancy E. Davidson, Fred Hutchison Cancer Research Center
Nicole F. Dowling, Centers for Disease Control and Prevention
Karen M. Emmons, Harvard University
Stanton L. Gerson, Case Comprehensive Cancer Center
Katrina Goddard, National Cancer Institute
Julie R. Gralow, American Society of Clinical Oncology
Chanita Hughes-Halbert, University of Southern California
Beth Y. Karlan, University of California, Los Angeles
Scott M. Lippman, University of California, San Diego
Laura Makaroff, American Cancer Society, Inc.

NATIONAL CANCER POLICY FORUM

## Addressing Resistance in the Development of Cancer Immune Modulator Therapeutics

**November 14-15, 2022**

National Academies of Sciences Lecture Room
2101 Constitution Ave, NW
Washington, DC 20001

**Statement of Task:**

A National Academies of Sciences, Engineering, and Medicine planning committee will plan and host a 1.5-day public workshop that will examine the current challenges related to resistance to immune modulator therapies and discuss potential policy levers that could help to overcome these challenges. The workshop will feature invited presentations and panel discussions on topics that may include:

- An overview of the unique types of immunotherapy resistance based on the causes of resistance, including whether resistance mechanisms vary among different agents, and gaps in current understanding.
- Policy challenges and opportunities to address the problem of resistance, including:
    - Criteria to move single agents into clinical trials.
    - Criteria to use single agents in combination therapy development (e.g., whether clinical response is necessary).
    - Criteria to assess cancer immunotherapy combinations in early-phase clinical trials.
    - The roles of preclinical modeling and clinical and predictive biomarkers (e.g., companion diagnostics, in vivo imaging) for assessing safety and efficacy.
    - The types of clinical trial designs needed for regulatory approval.
    - Use of big data to aid in determining the dominant drivers of cancer immunotherapy resistance and to predict immunotherapy responses.

The planning committee will develop the agenda for the workshop sessions, select and invite speakers and discussants, and moderate the discussions. A proceedings of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

**Planning Committee Pending**

# ABOUT THE FORUM

For more information, visit nationalacademies.org/ADIForum

#AgingDisabilityForum

## Forum on Aging, Disability, and Independence

The National Academies of Sciences, Engineering, and Medicine have formed the Forum on Aging, Disability, and Independence to foster dialogue and address issues of interest and concern related to aging and disability. This includes aging and the related disabling conditions that can occur, as well as aging with an existing disability. The Forum seeks to promote bridging of the research, policy, and practice interests of the aging and disability communities to accelerate the transfer of research to practice and identify levers that will effect change for the benefit of all. Of particular concern is promoting healthy aging, independence, and community living for older adults and people with disabilities.

### PERSON-CENTERED/PARTICIPANT-DIRECTED MODEL

Underpinning all aspects of achieving health and community living goals is a holistic, well-coordinated, person-centered, and participant-directed planning and implementation process. As depicted in the model below, this process should be directed by the individual in need, or by someone who either the individual has chosen or has been appropriately designated to direct and coordinate the process. The main factors that need to be coordinated include home and community settings; services and support; workforce; and financing. All of these factors exist within an environment that includes several key elements: quality; technology; research and evaluation; and policy. The Forum is focused on improving the understanding of the relationships that exist among all of these factors and examining ways to improve policies and environments that will ultimately promote independence and quality of life for older adults and people who have disabling conditions.

### COORDINATION

Many systems need to work together successfully to support healthy aging, independence, and community living for people with disabilities and older adults. While both medical and social services are key to keeping older adults and individuals with disabilities in the setting of their choice in the community, these two systems are not always well connected. Similarly, in many communities there is a divide between service systems for those who are under age 65 and those who are over age 65. A goal of the Forum is to improve system integration and access to person-centered supports and services that can improve quality of life for both populations. For some individuals, this could be in the form of a designated care coordinator, whereas for others it may mean ensuring that they have information about all available resources because they choose to be their own care coordinator.

### HOME AND COMMUNITY SETTINGS

Being an active member of a community is a priority for many people. A primary goal of the Forum is to foster access to services and supports that allow people with disabilities and older adults to live safely in the setting of their choosing and have the supports they need in the workplace if they would like to continue working.

### SERVICES AND SUPPORT

Having access to services and supports can be critical to improving quality of life, maximizing independence, and preventing hospital re-admission. Services and supports can include assistance with dressing or cooking, social engagement,


**Model for Promoting Healthy Aging, Independence, and Community Living for People with Disabilities and Older Adults**

or provision of medical care. It is important to ensure that potential beneficiaries are aware of available resources and take advantage of them as appropriate.

## WORKFORCE

The nation faces a growing imbalance between the supply of and demand for its health care system as the number of older adults with complex health needs increasingly outpaces the number of workers with the knowledge and skills to adequately care for them. Similarly, health care professionals are often not well-informed about proper care for people with disabilities or the problems these individuals face as they age. Fundamental reforms are needed in the ways these populations receive care, including changes to workforce education and training so that the workforce can be utilized efficiently and effectively while also providing high-quality care.

## FINANCING

Although there are various sources of financing to support healthy aging and independent living services, they can be insufficient and difficult to access. Financing sources range from federal and state programs to non-profit foundations and philanthropic organizations. In addition, the private sector offers insurance (medical and long-term), and many commercial companies provide programs that can offset costs for assistive products under specified conditions. However, the individual (or family members) often finances some or, in some cases, all services that are received. Innovations in financing are needed. Preventive services are underdeveloped and "under-offered," resulting in greater expense in the long run, even though some services have found ways to cut costs while maintaining or even improving quality. The Forum examines ways to increase use of prevention strategies and provide financing that is more transparent and usable by people desiring these services.

## TECHNOLOGY

Technology products have improved functioning and quality of life for people with disabilities of all ages. They can range in complexity from a calendar to coordinate which days of the week different services will be provided to devices that facilitate mobility and beyond. This is an area with many possibilities to connect the needs of consumers, regulators, businesses, and product developers. It also involves assistance in a myriad of settings, such as home, transport vehicles, medical facilities, workplaces, and community venues.

## POLICY

Numerous social inequities and other barriers prevent older adults and people with disabilities, particularly those with multiple chronic conditions, from realizing their full potential for social and economic participation. The Affordable Care Act offers new opportunities, both to improve the service delivery system and to provide coverage for workers who become disabled. Yet the need for policy improvements involving equitable financing for health care, access to affordable, person-centered long-term supports and services, and workplace accommodation still remains.

## RESEARCH AND EVALUATION

As policy changes are made, new technologies are developed, and the workforce adapts, evaluation and research are needed to determine whether these changes are beneficial and to validate best practices and inform future directions. Given that there are limited resources, wise use of existing data and effective coordination of research by all sectors of the nation are essential.

## QUALITY

Quality is a key characteristic that encompasses all elements of the Forum's model. It is needed in any system supporting healthy aging, independence, and community living. If the systems in place are not of good quality, then they could break down, coordination could be lost, or individuals may lose trust in the people, research, and devices that are intended to help them achieve personal goals.

## FORUM GOVERNANCE AND ACTIVITIES

The Forum is self-governing. Thus, the Forum membership identifies the topics it wishes to address, and with assistance from staff, develops meeting agendas and identifies workshop topics. The Forum meets 2-3 times annually and also has working groups that plan workshops and other activities. Products include workshop proceedings; cooperative projects initiated by Forum members; independently authored articles concerning Forum topics; and derivative consensus studies.

### SPONSORS

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The John A. Hartford Foundation
The SCAN Foundation

### FORUM DIRECTOR

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NATIONAL ACADEMIES Sciences Engineering Medicine

# Forum on Aging, Disability, and Independence

## MEMBERSHIP ROSTER

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Senior Vice President and Director of Health and Technology
Education Development Center

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The Gerontological Society of America

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Centers for Disease Control and Prevention (CDC)

**Julie Bynum, MD, MPH**
Professor of Internal Medicine
Margaret Terpenning Collegiate Professor
Institute for Healthcare Policy & Innovation
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**Margaret L. Campbell, PhD**
Campbell & Associates Consulting
Consultants in Aging, Disability, and Technology Research and Policy

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Director, Hartford Center of Geriatric Nursing Excellence
Penn State University College of Nursing

**Terry Fulmer, PhD, RN, FAAN**
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Director, Cochlear Center for Hearing and Public Health
Johns Hopkins Bloomberg School of Public Health

**Sarita A. Mohanty, MD, MPH, MBA**
**President and CEO**
The SCAN Foundation

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Program Specialist
National Institute on Disability, Independent Living, and Rehabilitation Research
Administration for Community Living
US Department of Health and Human Services

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Georgia State University

**Katie Smith Sloan, MA**
President and CEO
LeadingAge

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Associate Professor
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Department of Epidemiology, Johns Hopkins Bloomberg School of Public Health

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**Fernando Torres-Gil, PhD**
Professor
Director, Center for Public Research on Aging
Luskin School of Public Affairs
University of California, Los Angeles

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NATIONAL ACADEMIES Sciences Engineering Medicine

**Family Caregiving for People with Cancer and Other Serious Illnesses**

**Workshop Planning Committee Members, Moderators, and Speakers Biosketches**

**Kimberly D. Acquaviva, PhD, MSW, CSE, FNAP**
University of Virginia School of Nursing

Kimberly D. Acquaviva, PhD, MSW, CSE, FNAP serves as the Betty Norman Norris Endowed Professor at the University of Virginia School Of Nursing. Prior to coming to UVA in August 2019, she spent fifteen years as a faculty member at the George Washington University (GW) School of Nursing and the GW School of Medicine and Health Sciences. As a social worker teaching within a school of nursing, her scholarship is interdisciplinary and collaborative. Her scholarly work focuses on LGBTQ aging and end-of-life issues, and her clinical work has been with patients and families facing life-limiting illnesses in both hospital and hospice settings. Her book, ***LGBTQ-Inclusive Hospice & Palliative Care: A Practical Guide to Transforming Professional Practice***, was published by **Harrington Park Press** and distributed by **Columbia University Press**. The book was awarded first place in the AJN Book of the Year Awards in the Palliative Care and Hospice Category. She's the host of **em dash podcast**, a show that explores the lived experiences of patients and healthcare professionals in the healthcare arena.

Dr. Acquaviva has a PhD in Human Sexuality Education from the University of Pennsylvania Graduate School of Education, an MSW from the University of Pennsylvania School of Social Policy and Practice, and a BA in Sociology from the University of Pennsylvania College of Arts and Sciences. She is an **AASECT-Certified Sexuality Educator**.

**Rebekah SM Angove, PhD**
Patient Advocate Foundation

Rebekah SM Angove, PhD is a public health professional and leader in patient engagement with over 10 years of experience. Through her PhD training and real world experience in public health, she has extensive expertise in the principles and methodology of community engagement, participatory processes, and the integration of patient experiences and perspectives into healthcare, research, and policy. She has served as Principal Investigator (PI) or co-PI on National Institutes of Health, Robert Wood Johnson Foundation, and Patient Centered Outcomes Research Institute sponsored projects focused on integrating underserved communities into research and care initiatives. Her work focuses on integrating the patient perspective into all aspects of healthcare, while building real world evidence around the patient experience of social needs navigation and Social Determinants of Health to support

healthcare transformation, direct service improvement and policy recommendations. She is active in national committees and as an engaging speaker bridging the needs of the patient community with emerging issues in healthcare.

Dr. Angove currently serves as Vice President of Patient Experience and Program Evaluation at Patient Advocate Foundation (PAF), providing strategic oversight and thought leadership to improve the patient experience and impact of PAF's direct services. Dr. Angove serves as the Director of PAF's recently launched Patient Insight Institute, strategically partnering with research, healthcare, and policy leaders to generate patient-centered evidence and insights. The Institute draws from the 150,000 racially and economically diverse patients served annually by PAF, who are often struggling with challenges stemming from Social Determinants of Health and exacerbated by a chronic or complex condition.

**Allison J. Applebaum, PhD**
Memorial Sloan Kettering Cancer Center

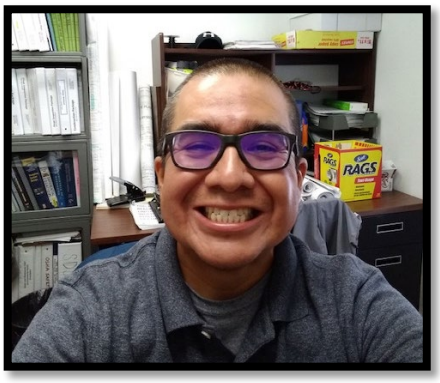
Allison Applebaum, PhD, is an Associate Attending Psychologist in the Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center (MSK), and an Associate Professor of Psychology in Psychiatry at Weill Cornell Medical College. She is the Founding Director of the Caregivers Clinic at MSK, housed in the Counseling Center. The Caregivers Clinic is the first of its kind and provides comprehensive psychosocial care to family members and friends of patients who experience significant distress and burden as a result of their caregiving role.

Dr. Applebaum's program of research focuses on the development and dissemination of psychosocial interventions for cancer caregivers, as well as understanding the impact of caregiver psychosocial wellbeing, prognostic awareness and communication skills on advanced care planning. She has published over 100 articles, reviews, and book chapters on these topics, and is the editor of the textbook *Cancer Caregivers* (Oxford University Press, 2019). Dr. Applebaum has received competitive funding for her research, including awards from the National Cancer Institute, the National Institute of Nursing Research, the American Cancer Society, the T.J. Martell Foundation, and the van Ameringen Foundation.

**Jennifer Moore Ballentine, MA**
California State University Shiley Haynes Institute for Palliative Care

Jennifer Moore Ballentine, MA, has more than 20 years' experience in hospice and palliative care, healthcare ethics and public policy, adult education, change design, and nonprofit leadership. As Executive Director of the California State University (CSU) Shiley Haynes Institute for Palliative Care, she oversees this unique enterprise developing innovative online and in-person curriculum for palliative care clinicians and other healthcare professionals caring for people with serious illness worldwide, as well as students in the healthcare professions throughout the CSU system. Her past leadership positions include President of The Iris Project; Vice President for Hospice Analytics; Executive Director of Life Quality Institute; and Director of Professional Programs for the

Colorado Center for Hospice and Palliative Care. She also serves with several national projects committed to improving quality in palliative care: the NHPCO Palliative Care Advisory Council, the Patient Quality of Life Coalition Steering Committee, and the NASEM Roundtable on Quality Care of People with Serious Illness. Ms. Ballentine has presented hundreds of educational workshops and keynotes at state and national conferences and is published widely in clinical literature, textbooks, and trade press. Ms. Ballentine holds a Master's degree with graduate honors in End-of-Life Studies from Regis University, a professional advancement certificate in gerontology from University of Colorado–Colorado Springs, and a Bachelor's degree, Phi Beta Kappa, from Oberlin College.




**Elton Becenti, Jr.**
Indian Health Service
Family Caregiver

Elton Becenti Jr., is a member of the Navajo Nation. He is an engineer at the Indian Health Service in the Division of Sanitation Facilities and Construction where he works on programs that bring running water and onsite wastewater facilities to homes on the Navajo Nation. Mr. Becenti has been a caregiver for both his parents. Mr. Becenti holds a Bachelors in Science and Civil Engineering from New Mexico State University.

**Janice F. Bell, PhD, MPH, MN, FAAN**
University of California, Davis

Janice F. Bell, MN, MPH, PhD, FAAN, is the Western Health Advantage Endowed Professor and Associate Dean for Research at the Betty Irene Moore School of Nursing at UC Davis. She is also a founding faculty member of the school's Family Caregiving Institute, an initiative dedicated to discovering and disseminating knowledge to improve systems to support family caregivers. She holds a PhD in Health Services Research and master degrees in public health and community nursing from the University of Washington.

Dr. Bell's work focuses on serious illness care models with a focus on family caregivers. She leads the evaluation of the Alameda County Care Alliance (ACCA) Advanced Illness Care Program, a lay "Care Navigator" intervention innovated by a consortium of San Francisco Bay Area African American churches to address advanced illness care disparities among persons with serious illness and their caregivers. Bell is also co-Principal Investigator on a project to evaluate the California state-funded expansion of services in the Caregiver Resource Center network. This includes the roll-out of a new technology application called *CareNav™*, a user-friendly tool designed to help families navigate the complexities of the caregiving journey by providing access to information, care consultation, resources and referrals.

**Cathy J. Bradly, PhD**
University of Colorado Comprehensive Cancer Center

Cathy J. Bradley, PhD, is the Associate Dean for Research in the Colorado School of Public Health and the Deputy Director of the University of Colorado Comprehensive Cancer Center. She holds the Bunn Chair in Cancer Research. Prior to joining the University of Colorado, she was the founding Chair of the Department of Healthcare Policy and Research, and Associate Director of Cancer Prevention and Control at Virginia Commonwealth University School of Medicine. Dr. Bradley is an internationally recognized expert in health services research and health economics. Her expertise is in labor market outcomes of cancer survivors, health policy, and health disparities. Dr. Bradley is on the editorial board of the *Journal of Cancer Survivorship*, and is a member of the National Academies of Sciences, Engineering, and Medicine's National Cancer Policy Forum.

**Malcoma Brown-Ekeogu**
Caregiver

Malcoma Brown-Ekeogu is a care partner for her husband diagnosed with the behavioral variant of Frontotemporal Degeneration (bvFTD).

She is a volunteer member of the Georgia Alzheimer's and Related Disease committee, Alter Dementia Advisory and design team, Emory Roybal Center for Dementia Caregiving Mastery and Order of the Eastern Star.

**Abena Apau Buckley, MBA**
Farm Production and Conservation, US Department of Agriculture

Abena Apau Buckley, MBA, is originally from Ghana. Ms. Buckley is currently a Customer Experience Officer for the US Department of Agriculture's (USDA) Farm Production and Conservation (FPAC) mission area. She came to the US in 1999 to attend the University of Virginia for undergraduate studies and then decided to come to the DC area after graduation. The plan was to work for a few years and then go back overseas for graduate school, but Ms. Buckley met her husband through friends and decided to stay in the US. Abena lost her husband to cancer about 4 years ago, but they had 2 beautiful children (2 boys ages 4 and 8) in the time they had together. Her boys keep her on her toes!

Abena joined the U.S. Department of Agriculture's Farm Production and Conservation (FPAC) in June 2019. In her current role as the FPAC Customer Experience Officer, she supports FPAC by leading efforts to assess the effectiveness and efficiency of customer-facing programs, policies, and processes across the four FPAC agencies. These efforts include internal/external survey development, journey mapping, and cultural change activities to embed a customer experience approach across FPAC. Abena has always loved doing work that allows her to see the real customer who benefits from the work.

In her free time, Abena falls asleep on the couch while pretending to watch a movie. She enjoys any materials (books, podcasts, leadership groups) that support women's empowerment efforts. Abena considers herself to be a (rather basic) foodie and loves to travel. Her father was a commercial pilot and her family lived in many different places growing up (the Middle East, the UK, Ireland). Abena's favorite thing to do is to travel to new places and organize her day around the places she will be eating that day.

**Julie Bynum, MD, MPH**
University of Michigan

Julie Bynum, MD, MPH, is the Margaret Terpenning Professor of Internal Medicine in the Division of Geriatric and Palliative Medicine, Vice Chair for Faculty Affairs for the Department of Internal Medicine, Research Professor in the Institute of Gerontology, Geriatric Center Associate Director for Health Policy and Research, and a member of the Institute for Healthcare Policy and Innovation. Dr. Bynum received her medical and public health degrees from Johns Hopkins, did her residency and chief residency at Dartmouth, and completed specialty training in Geriatric Medicine back at Johns Hopkins. She then joined the faculty at Dartmouth Medical School where she received prestigious career development awards from the Robert Wood Johnson Physician Faculty Scholar Program and the National Institute of Aging Beeson Scholar Program before joining the faculty at University of Michigan.

Dr. Bynum is known for leading interdisciplinary research teams to study questions about the complex drivers of quality and costs for older adults and how to improve health care policy and performance using national administrative data, particularly for people living with dementia or nearing the end of life. In addition, she has been an Atlantic Philanthropies Health & Aging Policy Fellow, was a member of the National Academy of Medicine Committee that published "Vital Signs: Core Metrics for Health and Health Care Progress" and was recently a Deputy Editor of the Journal of the American Geriatrics Society. She is currently a member of the NASEM Forum on Aging, Disability and Independence and on a NASEM Consensus Committee on "Building Data Infrastructure for Patient Centered Research." Dr. Bynum leads a robust portfolio of research largely focusing on health and health care for people living with dementia including a National Institute of Aging P30 Center to Accelerate Population Research in Alzheimer's and studies that examine the quality of care, diagnosis, and treatment of people with living with dementia in the community, long term care, and assisted living.

**Grace Campbell, PhD, MSW, RN**
Duquesne University

Grace Campbell, PhD, MSW, RN, is an Assistant Professor at the Duquesne University School of Nursing. She also holds adjunct appointments at the University Of Pittsburgh School Of Medicine, Department of Obstetrics, Gynecology, and Reproductive Science and the Hillman Cancer Center Biobehavioral Oncology Group. She is a founding faculty member of the UPMC Magee Gynecologic Oncology Family Caregiver Advocacy, Research, and Education (CARE) Center. Her research focuses on characterizing and intervening on cancer- and treatment-related functional limitations. She is currently Co-Lead for "SmartRehab: mHealth A Systemwide Scale-Up Project" at the University of Pittsburgh's National Center on Family Support, funded by the National Institute for Disability, Independent Living, and Rehabilitation Research.

Dr. Campbell is a Certified Rehabilitation Registered Nurse and a Fellow of the Association of Rehabilitation Nurses. (ARN) She is a member of the Board of Directors of ARN and represents that organization on the NASEM Roundtable on Quality of Care for People with Serious Illness. She was a member of the 2021 NASEM Consensus Study Report, "Diagnosing and Treating Adult Cancers and Associated Impairments." She is a member of the American Society for Clinical Oncology, serving as a Quality Training Program Coach. She is also a member of the Oncology Nursing Society, American Congress of Rehabilitation Medicine's Cancer Networking Group, and the Multinational Association of Supportive Care in Cancer.

**Jane Carmody, DNP, MBA, RN**
The John A. Hartford Foundation

Jane Carmody, DNP, MBA, RN, FAAN is a Senior Program Officer at The John A. Hartford Foundation, a national private foundation dedicated to improving the care of older adults. Her portfolio of grants includes programs to create age-friendly public health systems, strengthen community-based services for older adults, disseminate dementia care programs and resources, and improve emergency department care and surgical care for older adults.

**Loretta Christensen, MD, MBA, MSJ, FACS**
Indian Health Service

Loretta Christensen, MD, MBA, MSJ, FACS, an enrolled member of the Navajo Tribe, serves as the chief medical officer of the Indian Health Service (HIS). The IHS, an agency within the U.S. Department of Health and Human Services, is the principal federal health care provider for American Indians and Alaska Natives (AI/AN). As the CMO, Dr. Christensen is IHS' lead expert on medical and public health topics, giving technical consultation and guidance to the IHS Office of the Director and IHS staff throughout the country on AI/AN health care policies and issues. She provides national leadership for clinical and community-based health programs of the agency, and serves as the primary liaison and advocate for IHS health professionals.

**Sara Damiano, LCSW, ACHP-SW**
Ascension

Sara Damiano is the Ascension national director of palliative care overseeing the strategy and services of 200 specialty level staff, spanning across 12 markets, in 55 inpatient locations, 19 outpatient clinics, and 2 community based locations. In this role, she is responsible for the overall palliative care strategy with a focus on increasing access and referrals to specialty level palliative care services, enhancing primary palliative care, and integration with population health and value based care initiatives.

Previously, she served as the palliative care system director at Michigan's largest healthcare system-Beaumont Health, where she was responsible for leading the corporate strategy and operations for the clinical service line across 8 hospitals and outpatient services. Earlier in her career, she served as a manager of care management with Alliance Health, as a research recruiter with the San Francisco Public Health Department, and as a disability examiner with Social Security Disability.

She has more than 10 years of health care experience with leadership roles in palliative care, advance care planning, and care management. She is a licensed clinical social worker, certified case manager, and holds advanced certification in hospice and palliative care as a social worker. She earned a dual master's degree from the University of Southern California, Los Angeles in social work and gerontology as well as a bachelor's degree in sociology with a minor in gender and health from the University of Michigan, Ann Arbor. She is a member of the National Association of Social Workers, American College of Healthcare Executives, and American Academy of Hospice and Palliative Medicine.

**Catherine (Cait) M. DesRoches, DrPH**
Harvard Medical School and OpenNotes

Catherine (Cait) DesRoches, DrPH, is Associate Professor of Medicine at Harvard Medical School and a health policy and data nerd with expertise in emerging trends in health care delivery. A graduate of the University of Massachusetts School of Public Health, and the Joseph P. Mailman School of Public Health at Columbia University where she received her doctoral degree, Cait has also held research and faculty positions at Mathematica Policy Research, Simmons College School of Social Work, and the Harvard T.H. Chan School of Public Health. She currently serves as the Director of OpenNotes, a research-based initiative focused on improving health care through data transparency.

**Heidi Donovan, PhD, RN**
University of Pittsburgh

Dr. Donovan's research and practice is in the development of education and support programs for families facing cancer. Her program of research, funded by the National Institute of Nursing Research, the National Cancer Institute, and the Oncology Nursing Society has tested innovative strategies and support systems to help families navigate the challenges of living with advanced cancer. She was the Study Chair and Principal Investigator of a 3-arm Randomized Controlled Trial evaluating web-based symptom management interventions for women with recurrent ovarian cancer. She was Multiple Principal Investigator with Dr. Paula Sherwood of the initial SmartCare trial of a web- and telephone-based intervention to support family caregivers of patients with a primary malignant brain tumor. She is currently the Principal Investigator and Co-Director of the first National Center on Family Support funded by the Administration for Community Living.

Dr. Donovan is the co-founder and Director of the GynOnc Family CARE Center at Magee-Womens Hospital of the University of Pittsburgh Medical Center, where her team provides support and education to family caregivers of patients with gynecologic cancer.

**Alexandra Drane**
ARCHANGELS

Alexandra Drane is co-founder and CEO of ARCHANGELS. She served as Wellness Expert for Prudential, and co-founded Eliza Corporation (acquired by HMS Holdings Corp: HMSY), Engage with Grace, and three other companies (all boot-strapped). A serial entrepreneur, she is also a cashier-on-leave for Walmart. She believes communities are the front line of health, that caregivers are our country's greatest asset, and that we need to expand the definition of health to include life.

Ms. Drane sits on the Board of Advisors for RAND Health, the Leadership Council for the Rosalynn Carter Institute, the Entrepreneurs Council for The United States of Care, the Board of Advisors for Open Notes, and Harvard Medical School's Executive Council of the Division of Sleep Medicine. She is a Governor appointed member of the Executive Committee for the Board of Directors for MassTech, a member of the Board of Directors of C-TAC and has served as a vice chair of the Trustee Advisory Board at Beth Israel Deaconess Medical Center from 2012-2020 and is delighted to return to this role. She was named to the first ever Care100 list in 2020, a Top Women in Healthcare's Entrepreneur of the Year by PR News, one of Disruptive Women in Health Care's Women to Watch, one of Boston Globe's Top 100 Women Leaders, and listed in Boston Business Journal's "40 Under 40", as well as an inventor on multiple patents. Ms. Drane joined Prudential Financial in a film series called "The State of US" that generated close to two billion impressions. She has one hobby outside of her passion for revolutionizing health care, and her love of family and adventure…car racing.

**Fayron Epps, PhD, RN, FAAN**
Emory University

Fayron Epps, PhD, RN, FAAN, is a nurse with over 20 years of experience and is currently serving as an Assistant Professor at Emory University, Nell Hodgson Woodruff School of Nursing and the Principal Investigator of the Faith Village research lab. Dr. Epps is an active member with numerous professional organizations. She currently serves on the Board of Directors for the Southern Gerontological Society, Alzheimer's Association Georgia Chapter, and Meals on Wheels Atlanta. She also serves on the Leadership Core of the Public Health Center of Excellence in Dementia Caregiving at the University of Minnesota. Her career goal as a nurse scholar is to promote quality of life for families affected by dementia through research, education and service. Her program of research involves evidence-based practices for promoting quality of life for African Americans with dementia and their family caregivers. She is particularly interested in exploring way religious activities and spiritual connectedness can promote meaningful engagement among persons with dementia. Dr. Epps oversees several faith-based research related projects. Her research has been sponsored by federal and private funding agencies.

Dr. Epps is also the founder of the only nurse-led dementia friendly congregation program, Alter. For this program, Dr. Epps and her interdisciplinary team partners with African American faith communities to provide them with the necessary tools and resources needed to support families facing dementia.

**Terri Fried, MD**
Yale University School of Medicine

Terri Fried, MD, is Professor of Medicine and Chief of the Section of Geriatrics. She also serves as Director of the Research Education Core and Co-Director of the Yale Pepper Center. Dr. Fried completed her undergraduate and medical school training at Harvard. After a primary care residency at Rhode Island Hospital, she completed a geriatrics fellowship at Harvard, where she also participated in a bioethics fellowship. Dr. Fried has a record of continuous funding from the National Institutes of Health, the U.S. Department of Veterans Affairs, and foundations supporting her work to elucidate the preferences and priorities of older persons when faced with difficult healthcare decisions and to incorporate these perspectives into medical decision making. This work has led to the development of clinical approaches to elicit health outcome priorities of older persons. It has also involved the examination of how older adults balance competing considerations when faced with trade-offs in their healthcare decisions. Most recently, Dr. Fried completed two large clinical trials demonstrating the efficacy of a practical intervention with the potential for widespread dissemination to increase participation in advance care planning among middle-age and older adults in ambulatory care. This approach focuses on facilitating communication among patients and their potential surrogates Many of Dr. Fried's research findings have been published in high-impact journals, including *NEJM*, *JAMA*, *Annals of Internal Medicine,* and *JAMA Internal Medicine*.

Dr. Fried's work has been recognized with receipt of a Paul Beeson Physician Faculty Scholar award and a K24 Midcareer Investigator Award. She is also the recipient of the 2004 Outstanding Scientific Achievement for Clinical Investigation Award from the American Geriatrics Society.

**Peter Gee, MPP**
Caregiver and Nursing Student at NYU School of Nursing

After more than a decade together, Peter Gee's husband Jeff was diagnosed with the deadliest of all brain tumors, a glioblasatoma, in the fall of 2018. In addition to accessing cancer treatments at Memorial Sloan Kettering, both Jeff and Peter took full advantage of all the supports offered to patients and caregivers at the hospital, including Meaning-Centered Psychotherapy at the Caregivers Clinic. Mr. Gee now volunteers in MSK's Caregiver-to-Caregiver program. He has an undergraduate degree from the University of California, Berkeley, a Master's in Public Policy from Harvard University, and is currently an accelerated student at NYU Rory Meyers College of Nursing. He has been a longtime Board

member of Community Healthcare Network, a federally-qualified health center serving over 80,000 New Yorkers with primary and behavioral healthcare.

**Pamela S. Hinds, PhD, RN, FAAN**
George Washington University

Pamela S. Hinds, PhD, RN, FAAN, is the Executive Director of the Department of Nursing Science, Professional Practice, and Quality, the William and Joanne Conway Endowed Chair in Nursing Research, and the Research Integrity Officer at Children's National Health System in Washington, D.C., and a Professor of Pediatrics at the George Washington University, School of Medicine and Health Sciences in Washington, D. C. She is adjunct professor for the University of Pennsylvania, School of Nursing, Johns Hopkins University, School of Nursing, the University of Maryland, College of Nursing, and the Fudan University of Shanghai, China. Dr. Hinds received her undergraduate degree magna cum laude from the University of Vermont, Burlington, VT and her M.S.N. and Ph.D. degrees from the University of Arizona, Tucson in Psychiatric Nursing (summa cum laude) and Clinical Nursing Research, respectively.

For more than three decades, Dr. Hinds has created and led research related to the pediatric cancer experience, quality of life, fatigue and altered sleep during the treatment of pediatric cancers, and end-of-life communication and decision making. She served on the Institute of Medicine (IOM) committee on end-of-life and palliative care for children in America (2003) and the National Quality Forum panel on palliative and end-of-life care in America, the Institute of Medicine (IOM) committee on Dying in America (2014) and is currently serving on the National Academies of Sciences, Engineering and Medicine Roundtable on Quality Care for People with Serious Illness (2016-2022), the National Cancer Institute's Moonshot Tolerability Steering Committee (2019-2021), and the Committee on Childhood Cancers and Disability (2020-2021).

Dr. Hinds is an Oncology Nursing Society Distinguished Nurse Researcher and the Association of Pediatric Oncology and Hematology Distinguished Nurse Researcher. She was the inaugural chair of the Nurse Scholars for the Children's Oncology Group and the inaugural Co-Director for the Patient-Reported Outcomes (PRO) Resource Center for the Children's Oncology Group. She served on the National Cancer Institute Symptom and Quality of Life Scientific Committee, and the National Institute of Nursing Research Ad Hoc Evaluation Advisory Committee, End-of-life and Palliative Care Science, and is the Editor-in-Chief for the journal, *CANCER NURSING: An International Cancer Journal*. Dr. Hinds was named the Alumna of the Year in 2012 for the College of Nursing at the University of Arizona, received the 2015 Mentoring Award for Excellence in Clinical Research at Children's National Health System, and received the inaugural Nancy Klein Mentoring Award from the Association of Hematology/Oncology Nurses in 2016. She is the 2020 recipient of the HPNA Distinguished Nurse Researcher Award in Palliative Care and the 2020 Nightingale Award from the American Nurses Association and the Washington Post.

NATIONAL ACADEMIES Sciences Engineering Medicine

**Lyn-Tise Jones, MA**
Family Caregiver and Care Navigator

*Dear Mom,*
*Thank you for being there to witness me take my first breath. I hope you know that as painful as it was, it was an absolute honor to be there holding your hand as I witnessed you take last. It is with tears in my eyes, confusion in my mind, and a ripped heart that I write this note to you. Your untimely death is something that I'll never understand. I know that I don't get to choose the outcome of anyone's life course but I can't stop wrestling with the question of why it had to be your time.*

*I'll miss your laughter, your cooking, all of your stories, our last minute trips, all of the little silly things you bought me that I had absolutely no use for, and the way we both appreciated the sound of a beautiful wind chime. You are still my girl, through and through, right or wrong, you were my world!*

*Well, Mom, there are simply not enough words to describe how much I'll miss you and the pain I feel inside. The fact that I have think about going on without your physical presence causes me grief beyond explanation. While all of that is true, it is also true that we will get through these hard days and honor your legacy. Your grandkids will continue to hear about how some of your most tender moments revolved around them. They love you so much, Mom. I promise to buy them lots of things that don't make sense. I am not signing-up to buy 100 senseless items but I promise to not let you down, Mom--I'll concede; I won't even put up a fuss about it.*

*Mom, you took a piece of my heart with you when you left but the other pieces that remain will forever cherish you. Thank you for everything that you've taught me, done for me, shared with me, and most of all, how you loved me! Until we meet in Heaven, I'll stand up straight, keep it pushing and honor your legacy by unselfishly supporting our family and our community.*

*All my love,*
*Lyn-Tise*

I wanted to start my bio with the final letter written to my beloved mother, Yolanda Jones, whom I lovingly served as her primary caregiver before she transitioned to Heaven in February 2021. She passed away from stage 4 cancer. It was an honor to serve my mother.

My professional experience includes being a Community-based scholar and entrepreneur. I proudly hails from San Francisco, CA. I continue to be unwaveringly dedicated to ensuring equitable outcomes in underserved communities. My ability to connect my similar life experiences with my career endeavors is what truly sets me apart from the rest. Serving in various sectors of the community from working as a site coordinator and connector in educational facilities to serving as an active leader in the local government, I am no doubt a very well-known advocate and valuable asset to the community. Overall, my passion and strong desire for the advancement of underserved communities and neglected areas of society, continues to drive her to higher levels of success by delivering concrete, measurable and positive outcomes.

**Randy A. Jones, PhD, RN, FAAN**
University of Virginia Comprehensive Cancer Center

Randy A. Jones, PhD, RN, FAAN is a tenured Full Professor and the Associate Dean for Partner Development and Engagement at the University of Virginia School of Nursing and the Assistant Director of Outreach Recruitment and Engagement at the University of Virginia Comprehensive Cancer Center.

Throughout his career of continuous research funding, Dr. Jones has been committed to advancing health equity, diversity, community engagement, and interprofessional collaborations as it relates to research, teaching, service. His research and publications focus on health disparities, prostate cancer, chronic illness, and decision-making. He has conducted multiple studies on screening and treatment decision making as it relates to cancer, with an emphasis among African Americans. His program of research has expanded to include palliative care and caregivers' interactions with patients. He has received funded research grants (over $11.5 million) from organizations such as the National Institutes of Health (NIH), Robert Wood Johnson Foundation, American Cancer Society, and the American Nurses Foundation. He is currently Principal Investigator on a NIH R01 funded study testing an interactive decision aid for patients with advanced prostate cancer. Dr. Jones' program of research in developing and testing an interactive decision aid for those men who were diagnosed with advance prostate cancer may help patients with prostate cancer make informed, shared decisions about treatment. His program of research has implications for other chronic illnesses as well. Jones research aims to help decrease decisional regret and enhance quality of life among patients with chronic diseases and aid in better patient-centered care and precision medicine.

Dr. Jones' national reputation in health disparities and cancer research, has resulted in a number of recognitions, awards and honors. In addition, he has been invited to serve on several national and international impactful organization boards, such as the National Black Nurses Association, the National Institutes of Health, American Academy of Nursing, the Oncology Nursing Society, the Robert Wood Johnson Foundation, and The National Academies of Medicine's National Cancer Policy Forum, to name a few. He has published extensively in peer-reviewed journals.

**Jason Karlawish, MD**
University of Pennsylvania

Jason Karlawish, MD, is a physician and writer. He cares for patients at the Penn Memory Center, which he co-directs. A Professor of Medicine, Medical Ethics and Health Policy, and Neurology at the University of Pennsylvania, his research focuses on issues at the intersections of bioethics, aging and the neurosciences. As leader of the Penn Program for Precision Medicine for the Brain (P3MB) he and his colleagues have investigated the development and translation of Alzheimer's disease treatments and biomarker-based diagnostics and pharmaceuticals. Current work examines the personal and clinical impacts of caregivers' experiences of lucidity in persons with advanced dementia, supported decision making, and the disease experience of persons living with preclinical neurological diseases. His essays have

appeared in Forbes.com, The Hill, the New York Times, the Philadelphia Inquirer, STATnews and the Washington Post. He is the author of *The Problem of Alzheimer's: How Science, Culture and Politics Turned a Rare Disease into a Crisis and What We Can Do About It* (St Martin's Press 2021), is an account of how Alzheimer's disease became a crisis and the steps needed to address it.

**Erin E. Kent, PhD, MS**
UNC Chapel Hill Gillings School of Global Public Health

Erin E. Kent, PhD, MS, is an Associate Professor and Associate Chair in Health Policy and Management at the UNC Chapel Hill Gillings School of Global Public Health. She is also a full Member of Lineberger Comprehensive Cancer Center and a Health Services Research Fellow at the Cecil G. Sheps Center, currently working with the Rural Health Research Program. Her disciplinary background is in epidemiology, mixed methods research, and health services research. Dr. Kent focuses on the impact of social context on health outcomes for individuals with serious illness and their families, with 117+ publications in patient- and family-centered outcomes research. Her current work is primarily focused on serious illness caregiving. She formerly served as a Program Director and Scientific Advisor for the Outcomes Research Branch at the National Cancer Institute.

**Rebecca Kirch, JD**
National Patient Advocate Foundation

Rebecca Kirch, JD, is Executive Vice President of Policy and Programs for the National Patient Advocate Foundation (NPAF) based in Washington, DC. In this role, she provides strategic focus and leadership in bringing patient and caregiver voices and values to the forefront of health reform efforts through influential advocacy and grassroots mobilization. As a leading health policy expert and advocate in her field, Rebecca is dedicated to advancing person-centered policies and practices that put people at the heart of healthcare.

Prior to joining NPAF in 2016, Rebecca served for 15 years with the American Cancer Society and its advocacy affiliate, the American Cancer Society Cancer Action Network, directing development and execution of coordinated quality of life and survivorship research, policy and advocacy activities.
A frequently invited speaker on patient and family engagement about person-centered care priorities and practices, Ms. Kirch has authored numerous articles and book chapters, including publications in the New England Journal of Medicine, Archives of Internal Medicine, Health Equity, JAMA Oncology, Health Affairs, Circulation and other professional journals. She is the recipient of numerous national awards, has been featured in multiple media outlets and also serves on National Quality Forum's MAP Coordinating Committee and Consensus Standards Approval Committee and ICER's New England Comparative Effectiveness Public Advisory Council.

Among other advisory committees and advocacy coalitions, Ms. Kirch is currently an active participant of the National Academy of Science, Engineering and Medicine's Quality Care for People with Serious Illness Roundtable, co-chair of the Quality of Life and Person-Centered Care task force for the American Congress of Rehabilitation Medicine and a board member for children's oncology Care Camps.


**Roger Glen Kirwin**
Family Caregiver

Husband of 29 years to Elizabeth who died of cancer in 2021, Roger originally hails from Liverpool in England and became a naturalized US citizen in 2002. With 21 years in the motorcycle industry followed by 8 years as executive director of a historic site in Pennsylvania, he now owns a business specializing in suspension upgrades for motorcycles… and enjoys the ruthless pursuit of Germans in World War 1 living history reenactments.

**Wendy G. Lichtenthal, PhD, FT**
Memorial Sloan Kettering Cancer Center

Wendy G. Lichtenthal, PhD, FT is Director of the Bereavement Clinic and Associate Attending Psychologist in the Department of Psychiatry and Behavioral Sciences at Memorial Sloan Kettering Cancer Center (MSK) and Assistant Professor of Psychology in the Department of Psychiatry at Weill Cornell Medicine. She completed her undergraduate studies at The University of Chicago, her doctorate at the University of Pennsylvania, her clinical psychology internship at Payne Whitney/Weill Cornell Medicine, and a postdoctoral research fellowship in psycho-oncology at MSK, where she was Chief Research Fellow. As a licensed clinical psychologist, Dr. Lichtenthal's clinical practice focuses on supporting bereaved individuals as well as breast cancer patients. Her research has focused on grief and bereavement, meaning-making, intervention development, and cancer survivorship. It has been supported by the National Cancer Institute, the National Institute of Mental Health, the National Institute of Nursing Research, the American Cancer Society, the T.J. Martell Foundation, and MSK's Cycle for Survival. Dr. Lichtenthal was the recipient of the Kawano New Investigator Award from the International Psycho-Oncology Society in 2012 and the Research Recognition Award from the Association for Death Education and Counseling in 2019.

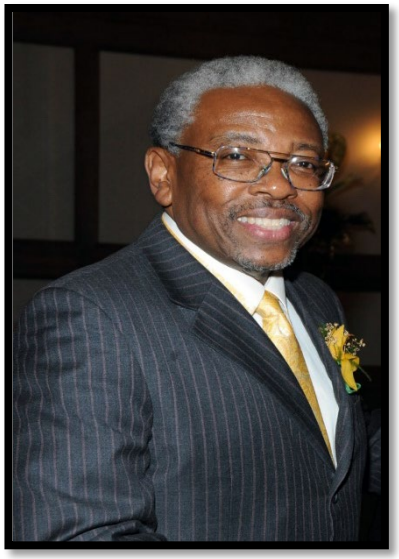
**Greg Link, MA**
Administration for Community Living
US Administration on Aging

Greg Link, MA, is the Director of the Office of Supportive and Caregiver Services with the Administration for Community Living/U.S. Administration on Aging (ACL/AoA), which oversees programs funded under the Older Americans Act (OAA), including Title III-B in-home supportive services, Title III-E National Family Caregiver Support Program as well as ACL's Alzheimer's disease programs. Greg and his team also provide general oversight and technical assistance to the aging network on a range of program areas, including Information and Referral, family caregiver support programs and policies, housing, employment, transportation, LGBT aging, and Holocaust Survivors.

Prior to ACL/AoA, Greg worked at the National Association of State Units on Aging where he provided technical assistance and training to states on family care giving, consumer direction, and transportation. Greg has also worked at the community level as a case manager and social services manager at Senior Friendship Centers in Fort Myers Florida. There, he oversaw the social services staff and the delivery of services funded by the Older Americans Act, state funds and Medicaid waivers.
Greg holds a bachelor's degree in psychology from the University of Central Florida and a Master of Arts in Government from Johns Hopkins University.

**Amy Melnick, MPA**
National Coalition for Hospice and Palliative Care

Amy Melnick, MPA is the Executive Director of the National Coalition for Hospice and Palliative Care (NCHPC). Amy's career has focused on health care policy, legislative and regulatory advocacy, and Coalition building with diverse stakeholders. Amy guides the Coalition efforts towards improved communication, coordination and collaboration within the 13 national organizations representing the interdisciplinary hospice and palliative care field. Prior to joining the Coalition, Amy led public policy and advocacy efforts for the Arthritis Foundation and Heart Rhythm Society after serving on Capitol Hill for several years. Amy attended the London School of Economics and Political Science and received her undergraduate degree from Wellesley College and her Master of Public Administration from George Mason University.



**Clyde W. Oden, Jr., OD, MDiv, MPH, MBA**
Alameda County Care Alliance

The Reverend Doctor Clyde W. Oden, Jr., has served low-income communities of color, focusing on health care services and religious ministries. He is an optometrist and a retired health executive after serving for three decades as chief executive officer of one of the nation's largest Federal Qualified Health Centers (FQHCs) and retired as a pastor in the African Methodist Episcopal Church (AMEC), leading three Southern California congregations over nearly a quarter of a century

He is currently the Assistant Director of the Alameda County Health Care Alliance. The ACCA specializes in faith-based lay care navigation and intervention programs that serve individuals with advanced illness and their caregivers. This nonprofit community organization serves persons in Alameda, Contra Costa, and San Francisco counties.

**Randall A. Oyer, MD, FACC**
Penn Medicine Lancaster General Health and Perelman School of Medicine

Randall A. Oyer, MD, FACC, is a practicing medical oncologist at the Ann B. Barshinger Cancer Institute at Penn Medicine Lancaster General Health in Lancaster, Pennsylvania. Dr. Oyer serves a Clinical Professor of Medicine at the Perelman School of Medicine, the Medical Director of the Cancer Institute, Medical Director of Oncology, Chairman of Cancer Committee, Chair of the Oncology Physicians Advisory Council, and Medical Director of the Cancer Risk Evaluation Program at Penn Medicine Lancaster General.

Dr. Oyer is a member of the Cancer Service Line Executive Committee and the Cancer Service Line Quality Committee at the Abramson Cancer Center- University of Pennsylvania, Philadelphia. Dr. Oyer is also a member of the Board of Directors, and Immediate Past President of the Association of Community Cancer Centers, Rockville, Maryland. Dr. Oyer is an ex-officio Commissioner of the American College of Surgeons Commission on Cancer, representing the Association of Community Cancer Centers. He also is a member of the National Cancer Policy Forum at the National Academies of Science, Engineering, and Medicine.

**Devin Plote, PhD**
America's Health Insurance Plans

Devin Plote is a Clinical Policy Analyst for America's Health Insurance Plans (AHIP), the national association representing organizations that provide coverage for health care and related services. She is responsible for policy interpretation, advocacy development, and trend analysis in the areas of prevention and population health, women's and maternal health, and aging. Prior to working at AHIP, Devin was a University of Texas Graduate Archer Fellow, and she received her doctorate in Cancer Biology from the University of Texas at MD Anderson Cancer Center.

**Michael Reese-Wittke, MPA**
National Alliance for Caregiving

Michael Reese-Wittke, MPA, joined the National Alliance for Caregiving in 2016. He serves as the Vice President for Research & Advocacy and is a senior member of NAC's Executive Leadership team. He supported the organization's growth during a leadership transition and has expanded capacity within NAC's Research and Advocacy departments—focusing on bridging gaps between data and policy to address challenges facing family caregivers of older adults, people with disabilities, and those with serious or chronic conditions across the lifespan.

Mr. Reese-Wittke came to Washington D.C. through an internship with the Hinckley Institute of Politics. He earned a bachelor's degree in Social Work, with honors, from the University of Utah and a master's degree in Public Administration, with a concentration in non-profit management, from American University. Mr. Reese-Wittke has previously served as Chair of the National Association of Social Workers (NASW) Political Action for Candidate Election Committee and as a member of the NASW Metro Chapter Board of Directors. He is currently on the Board of Directors for the Friends of Theodore Roosevelt Island.

**Susan Reinhard, RN, PhD, FAAN**
AARP

Susan Reinhard, RN, PhD, FAAN, SVP at AARP, directs its Public Policy Institute, the focal point for state, federal and international policy research. Susan oversees PPI teams working on health security, financial security, and family, home, and community issues, and from that vantage point serves as editor-in-chief of Policy Plus Action: The AARP Public Policy Institute Newsletter. She also serves as Chief Strategist for the Center to Champion Nursing in America. She is a nationally recognized expert in health and long-term care, with extensive experience in conducting, directing and translating research to promote policy change. Previously, she served as Co-Director of Rutgers Center for State Health Policy, directing national initiatives to help people with disabilities live at home. She served three governors as Deputy Commissioner of the NJ Department of Health and Senior Services. Her research and policy expertise includes health care workforce, caregiving, consumer choice, community care options, and quality. A former faculty member at Rutgers College of Nursing, she is an American Academy of Nursing fellow. She holds a master's degree from the University of Cincinnati and a PhD from Rutgers University.

**Sheria G. Robinson-Lane, PhD, MSN, MHA, RN**
University of Michigan School of Nursing

Sheria G. Robinson-Lane, PhD, MSN, MHA, RN is an Assistant Professor at the University of Michigan School of Nursing in the Department of Systems, Populations, and Leadership. Dr. Robinson-Lane's work aims to reduce health disparities and improve health equity for diverse older adults and family caregivers managing pain and chronic illnesses such as Alzheimer's disease. Dr. Robinson-Lane's research addresses the ways in which older adults adapt to changes in health, and particularly how various coping strategies affect health outcomes. Her current work is focused on improving the ability of diverse older adults to successfully age in place through culturally responsive and community engaged care practices along with effective caregiver support. To this end, for more 14 years, she has developed and presented numerous presentations and publications on effective clinical practice and the care and symptom management of older adults with chronic disease.

As an expert in long-term care and hospice/ palliative care practice, Dr. Robinson-Lane has also done significant work over the past year providing community education on COVID-19, COVID vaccines, and managing care of the older adult during the pandemic. She has been featured in local, national, and international news outlets. Dr. Robinson-Lane completed her PhD in Nursing at Wayne State University in Detroit, along with a graduate certificate in gerontology. She also completed a postdoctoral fellowship in Advanced Rehabilitation Research Training at the University of Michigan Medical School in the Department of Physical Medicine and Rehabilitation.

**Dannell Shu, BFA, MWS**
Family Caregiver

Dannell Shu, BFA, MWS, is the mother of Levi, a boy born with severe brain damage and the diagnosis of uncertainty. For seven years she led his in-home ICU while collaborating with an extensive team of medical specialists, therapy and integrative providers, educational teams, and a staff of caregivers. Levi received palliative care in most of his care settings for the majority of his life. In 2014, while immersed in caregiving, Ms. Shu became a parent advocate to join the work of alleviating disparities, improving education, and fostering resilient families in need of palliative and hospice care. She has become regarded as an uplifting speaker, thought provoking writer and engaging educator.

Ms. Shu serves on the Pediatric Palliative Care National Task Force, is an appointed member of Minnesota's Palliative Care Advisory Council, and the Pediatric Palliative Care Coalition of Minnesota. As a Parent Faculty and Co-Investigator with the University of Minnesota's simulation and skills-based EOL workshop for pediatric fellows she is engaging in cross-disciplinary provider education. Ms. Shu has presented in numerous contexts, including the Minnesota Network of Hospice and Palliative Care Annual Conference, Crescent Cove's Pediatric Palliative Care Symposium, the End-of-Life Nursing Educational Consortium (ELNEC), and fundraising galas for nonprofits. She is thankful to have been instrumental in helping establish Crescent Cove, Minnesota's first pediatric palliative, hospice and respite home; currently one of three in the United States. A full list of her advocacy and nationally published writings can be found on MamaShu.org

**Rani E. Snyder, MPA**
The John A. Hartford Foundation

Rani E. Snyder, MPA, is Vice President, Program at The John A. Hartford Foundation. Ms. Snyder has over 25 years of experience working with preeminent health care institutions across the nation improving the care of older adults, identifying and guiding health care programs that have set the standard for medical best practices, increasing medical education opportunities, and maximizing resources to improve health care broadly. She brings that experience to The John A. Hartford Foundation where she coordinates initiatives that foster collaboration among academic institutions, hospitals and health care providers to build Age-Friendly Health Systems, support family caregivers, and improve serious illness and end-of-life care. She is a board member and past board chair for Grantmakers in Aging, a membership organization comprised of philanthropies with a common dedication to improving the experience of aging, a board member for the American Society on Aging, a fellow of the New York Academy of Medicine, and previously served as a Volunteer Long-Term Care Ombudsman for the State of Nevada Aging and Disability Services Division.

**Salom Teshale, PhD**
National Academy for State Health Policy

Salom Teshale is a Policy Associate on the National Academy for State Health Policy (NASHP)'s Behavioral Health, Aging, and Disability team and works on projects related to family caregiving and palliative care. Prior to joining NASHP, Salom was a postdoctoral fellow at the Administration for Community Living in the US Department of Health and Human Services and the University of Washington School of Medicine, where she conducted research on topics related to aging and well-being in adults aging with long-term disability. She holds a PhD from Brandeis University in social/developmental psychology, and a BA in psychology from the University of Chicago.

**Courtney Harold Van Houtven, PhD, MSc**
Duke University School of Medicine and Duke-Margolis Center for Health Policy

Courtney Van Houtven, PhD, MSc, trained as a health economist, is a Research Career Scientist at the Center of Innovation to Accelerate Discovery and Practice Transformation (ADAPT), Durham Veterans Affairs (VA) Health Care System. She is also a Professor of Medicine in the Department of Population Health Science at Duke University School of Medicine. Her research examines how family caregiving affects economic, health and health care outcomes of care recipients and caregivers. She is assessing the negative economic spillovers for caregivers of advanced cancer patients, including out-of-pocket costs, work changes and debt accumulation (R01 NCI: Siminoff, PI). Dr. Van Houtven is also interested in understanding how to best support family caregivers through pragmatic trials and strategies, including through better inclusion of caregivers as explicit members of the health care team. She strives to evaluate promising models of care, including how home-and community-based services can preserve Veteran independence and how the VA geriatric primary care medical home model of care affects quality of care and patient experience outcomes compared to usual primary care (IIR co-PI Nicki Hastings: 2017-2022).

She directs the VA-CARES Partnered Evaluation Center, an ongoing national evaluation of the VA's Caregiver Support Program (2014-2027) to rigorously assess supports and services affect caregiver and Veteran quality of life and health system outcomes. She is co-PI on the QUERI Program Project, "Optimizing Function and Independence" (2016-2025), in which she is working with operational partners in VA, clinical field staff, and a multidisciplinary research team to implement a family caregiver skills training curriculum nationally. Her RIVR project is a stakeholder-engaged mixed methods study to develop a person-centered population-based measure of Veteran 'home time.' Building upon this work, in a new R-01 from NIA/NIH she is working with a team to develop a person-centered measure of home time for persons living with dementia and their spousal caregivers (2021-2026) and will use machine learning to identify risk factors that interrupt the ability to remain in one's own home. Dr. Van Houtven mentors 4 current VA Career Development

scholars (Boucher, Shepherd-Banigan, Jacobs, Kaufman), one K01 scholar (DePasquale) and is a consultant on one CDA (Wyman).

**Jennifer L. Wolff, PhD**
Johns Hopkins University School of Public Health

Jennifer Wolff, PhD, is the Eugene and Mildred Lipitz Professor in the Department of Health Policy and Management and Director of the Roger C. Lipitz Center for Integrated Health Care at the Johns Hopkins Bloomberg School of Public Health and holds a joint appointment in the Division of Geriatric Medicine and Gerontology at the Johns Hopkins University School of Medicine. Dr. Wolff's research focuses on the care of persons with complex health needs and disabilities and applied studies and initiatives directed at better supporting them and their family caregivers within systems of care delivery.

Dr. Wolff has authored more than 150 peer-review papers, and 20 book chapters or reports on topics related to family caregiving and care delivery. Her research has been continuously funded by the National Institute of Health and other federal agencies and private foundations. She is a member of AcademyHealth, the American Society on Aging, and the Gerontological Society of America and has served on multiple expert panels and consensus committees convened by the National Academies of Sciences, Engineering, and Medicine on the topics of family caregiving, home-based care, and dementia care and services.

# Implementing the RAISE Family Caregivers Act

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2017, was signed into law in January 2018. It seeks to address the diverse and complex issues faced by family caregivers through the development of a National Family Caregiving Strategy. The RAISE Act consists of three key elements: the formation of the nation's first Family Caregiving Advisory Council; the development of a Report to Congress; and the creation of National Family Caregiving Strategy.

## The Family Caregiving Advisory Council

To form the council, ACL issued a call for nominations in the Federal Register in October 2018; 270 unique nominations were received. In selecting the nominees for appointment, ACL weighed breadth of experience, qualifications, and geographic and regional distribution to ensure the council reflected the dynamic nature of the family caregiving landscape. Of the council members selected, many are—or have been—either caregivers, people receiving support—or both.

In August 2019, the council convened in Washington, D.C. During the meeting—and subsequent in-person and virtual meetings—council members and guest speakers shared and discussed personal stories, results, and strategies from advocacy efforts, and findings of national research and state-driven task forces. Throughout 2020 and 2021, the council conducted substantive deliberations—moving to an online platform during the COVID-19 pandemic. Inherent in the council's work was a focus on balancing the perspectives and needs of caregivers of older adults with those of care partners and family members of people with disabilities.

Over the course of their deliberations, the council identified several unifying characteristics of family caregivers that must be acknowledged as we look for more holistic ways of supporting them:

1. A **significant personal relationship** or connection often exists between family caregivers and the people who receive support. Some caregivers provide assistance out of a wellspring of love and concern, but personal feelings are not always the driving force. Other caregivers provide care in response to tradition, culture, family expectation, and other factors. Often some combination of these reasons shapes the experience of family caregivers.

2. Many family caregivers are driven by the desire **to help maintain the independence, dignity, engagement, and/or quality of life** of the person they are supporting.

3. Caregivers often **provide support without a formal assessment** of their needs or of the person receiving support. They often learn "on the job," taking on tasks they do not know how to do, or do not feel comfortable doing, and have little access to training or assistance. Further, there is little recognition of the difficulty of their responsibilities.

4. The nature of **family caregiving is becoming ever more complex** in the modern era as it extends to more medical, administrative, and care coordination activities than ever before. Caregiving today can include complex medication management, dealing with insurance payers, operating electronic equipment and medical devices, and coordinating care across systems.

5. No matter how emotionally rewarding, caregiving can leave caregivers **financially, emotionally, and physically depleted, and socially isolated**.

## The Initial Report to Congress

The council's initial Report to Congress addresses each of the topic areas specified by Congress in the RAISE Act, and includes:

- The identification of challenges faced by family caregivers, including financial, health, and other challenges, and existing approaches to address such challenges.
- An overview of federally funded efforts to address those challenges.
- A discussion of how family caregiving impacts the Medicare program, the Medicaid program, and other federal programs.
- Recommendations to improve and better coordinate federal programs and activities to recognize and support family caregivers and improve the coordination of such federal programs and activities with state programs and other programs.

In addition to surveying existing literature, programs, and data about family caregiving, and with generous support made possible by an innovative public-private partnership, the council undertook a broad effort to engage the public for input to the report. Those efforts included a widely disseminated Request for Information (RFI) in 2019, listening sessions, focus groups, and interviews with 25 family caregivers whose stories and words are presented throughout the report.

In November 2020, the council adopted 26 recommendations to improve and better coordinate federal, state, tribal, and community programs and activities to recognize and support family caregivers. These recommendations are the framework of the forthcoming National Family Caregiving Strategy. They cover a range of critical issues the nation must address in bold and meaningful ways in order to demonstrate that it values the contributions of family caregivers.

## Looking Ahead: The National Family Caregiving Strategy

The RAISE Act is specific in its requirements for the scope of the National Family Caregiving Strategy. Using the 26 recommendations, and through further engagement with the public, the council will next turn its efforts to developing the Strategy. With the Act as a framework, the Strategy will identify actions that the federal government along with states, local communities, health and LTSS providers, and others can take to recognize and support family caregivers.

Like the Report to Congress, the Strategy will reflect the diverse needs and preferences of family caregivers and will include actions the nation can take to better-support family caregivers using family-centered approaches; assessment and service planning; greater respite options; more options for information, education, and training supports; strengthening financial security and addressing workplace issues; and fostering improvements in service delivery. When completed, the Strategy will provide a national roadmap towards greater recognition, assistance, inclusion, support, and engagement of family caregivers.

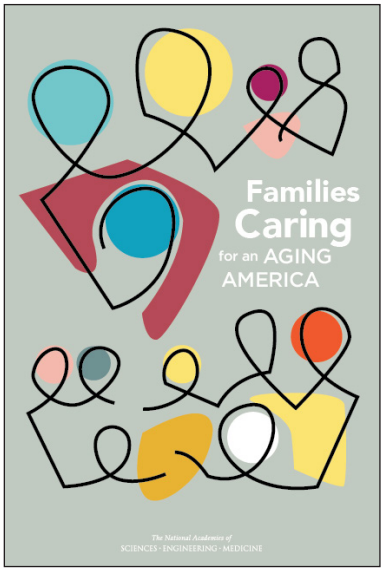
Learn more about the RAISE Family Caregivers Act and the Advisory Council at ACL.gov/RAISE.

Report

September 2016

IN BRIEF

# Families Caring for an Aging America




Millions of Americans are providing care and support to an older adult—a parent, spouse, friend, or neighbor—who needs help because of a limitation in their physical, mental, or cognitive functioning. For decades, demographers, gerontologists, health researchers and providers, economists, and other experts have raised concerns about the rapid aging of our population and its implications for the health care system; Social Security; and local, state, and federal resources. Far less attention has been given to family caregivers who provide the lion's share of long-term services and supports (LTSS) to our older adult population. Many are unaware that today, some family caregivers are expected to provide complex health care services once only delivered by licensed health care personnel in a hospital or other setting.

At least 17.7 million individuals in the United States are family caregivers of someone age 65 and older who has a significant impairment. The circumstances of individual caregivers are extremely varied. They may live with, nearby, or far away from the person receiving care. The care they provide may be episodic, daily, occasional, or of short or long duration. The caregiver may help with household tasks or self-care activities, such as getting in and out of bed, bathing, dressing, eating, or toileting, or may provide complex medical care tasks, such as managing medications and giving injections. The older adult may have dementia and require a caregiver's constant supervision. Or, the caregiver may be responsible for all of these activities.

With support from 15 sponsors, the National Academies of Sciences, Engineering, and Medicine convened an expert committee to examine what is known about the nation's family caregivers of older adults and to recommend policies to address their needs and help to minimize the barriers they encounter in acting on behalf of an older adult. The resulting report, *Families Caring for an Aging America,* provides an overview of the prevalence and nature of family caregiving of older adults as well as its personal impact on caregivers' health, economic security, and overall well-being. The report also examines the available evidence on the effectiveness of programs and interventions designed to support family caregivers. It concludes with recommendations for developing a national strategy to effectively engage and support them.

**An expert committee examines what is known about the nation's family caregivers of older adults and recommends policies to address their needs and help to minimize the barriers they encounter in acting on behalf of an older adult.**

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## RAPIDLY INCREASING NUMBERS OF OLDER ADULTS, SHRINKING FAMILIES

A number of factors underscore the urgency of addressing the needs of family caregivers. There is a growing gap between the demand for and supply of family caregivers for older adults. The demand for caregivers is increasing significantly not only because of the dramatic increase in numbers of older adults but also because the fastest growing cohort of older adults are those age 80 and older—the age when people are most likely to have a significant physical or cognitive impairment or both. At the same time, the size of American families is shrinking and the makeup of families is changing as more people do not have children, never marry, divorce, or blend families through remarriage. Moreover, half of family caregivers are employed.

## THE PERSONAL IMPACT OF FAMILY CAREGIVING

American families are more diverse—ethnically, racially, economically, religiously, and in many other ways—than ever. Their experiences and the older adults they care for are as varied as the nation's population. For some people, caregiving can instill confidence, provide meaning and purpose, enhance skills, and bring the caregiver closer to the older adult. For others, caregiving takes a significant toll. An extensive literature indicates that compared to non-caregivers, family caregivers of older adults are more likely to experience emotional distress, depression, anxiety, or social isolation. Some caregivers also report being in poor physical health, and some have elevated levels of stress hormones or higher rates of chronic disease.

The intensity and duration of caregiving and the older adult's level of impairment are consistent predictors of negative health effects for the caregiver. Family members who spend long hours caring for older relatives with advanced dementia, for example, are especially at risk. Other risk factors include low socioeconomic status, high levels of perceived suffering of the care recipient, living with the care recipient, lack of choice in taking on the caregiving role, poor physical health of the caregiver, lack of social support, and a physical home environment that makes care tasks difficult.

Family caregivers of significantly impaired older adults are also vulnerable to financial harm. Caregivers may lose income, Social Security and other retirement benefits, and career opportunities if they have to cut back on work hours or leave the workforce. They may also incur substantial out-of-pocket expenses that may undermine their own future financial security.

## SYSTEMIC BARRIERS

In order to fulfill the roles that they play, family caregivers must interact with a wide range of providers and navigate within a variety of systems. They interact with physicians, physician assistants, nurses, nurse practitioners, social workers, psychologists, pharmacists, physical and occupational therapists, direct care workers, and others. They serve as key information sources about older adults' health histories, their medications, previous treatments and surgeries, and adverse reactions to any drugs. They represent older adults in dealings with home health care agencies, physicians' and other providers' offices, hospitals, pharmacies, assisted living facilities, and nursing homes.

Yet, family caregivers are often marginalized in the delivery of health care and LTSS. Paradoxically, some providers exclude them from older adults' treatment decisions and care planning while also assuming they are able, have the knowledge, and are willing to perform essential tasks. Caregivers describe learning by trial and error and report fear of making a mistake.

## EFFECTIVE INTERVENTIONS ARE AVAILABLE

A growing body of research provides important insights into how to effectively support family caregivers. The

**The committee calls for a transformation in the policies and practices affecting the role of families in the support and care of older adults, stating that today's emphasis on person-centered care needs to evolve into a focus on person- and family-centered care.**

most effective interventions begin with an assessment of caregivers' risks, needs, strengths, and preferences. Education and skills training can improve caregiver confidence and ability to manage daily care challenges. Counseling, self-care, relaxation training, and respite programs can improve both the caregiver's and care recipient's quality of life. Some research also suggests that providing services, such as personal counseling and care management, may delay older adults' institutionalization and reduce re-hospitalization. Nevertheless, few caregivers have access to such services.

## AN URGENT NEED FOR ACTION

The committee calls for a transformation in the policies and practices affecting the role of families in the support and care of older adults, stating that today's emphasis on person-centered care needs to evolve into a focus on person- and family-centered care. The committee urges that the Secretary of Health and Human Services, in collaboration with the Secretaries of Labor and Veterans Affairs, and others, create and implement a National Family Caregiver Strategy that includes the following

- effective mechanisms to ensure that family caregivers are routinely identified in delivery of services to older adults with impairments;
- Medicare and Medicaid payment reform to motivate providers to engage family caregivers effectively;
- training of health care and LTSS providers to engage caregivers;
- dissemination and funding for evidence-based caregiver services;
- evaluation and adoption of federal policies that provide economic support to working caregivers; and
- expansion of the national data collection infrastructure to create a knowledge base about caregivers.

States also have an important role to play, as does the private sector. State agencies can learn from the states that have enacted job protections and expanded access to family leave for caregivers. Also, a public–private innovation fund could leverage private funding to accelerate research and development of assistive technologies, remote monitoring and sensing systems, telehealth applications, and other tools to assist family caregivers.

Because the future of caregiving for older Americans will be shaped not only by the growing numers of older adults needing care but also by the increasing diversity of older people and their families, all of the above actions should address the needs and values of diverse family caregivers.

To read the full text of the committee's recommendations, please refer to the recommendations insert.

## CONCLUSION

This report raises serious concerns about the current state of family caregiving of older adults in the United States. The impact of caregiving on families should not be ignored. If the needs of caregivers are not addressed, we risk compromising the well-being of our elders and their families. Taking on these challenges means seizing an opportunity to discover the potential societal benefits of effectively engaging and supporting family caregivers in the care of older adults—both economic and otherwise.

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