



National Comprehensive
Cancer Network®

NCCN Patient Advocacy Summit:

Better Information for Better Outcomes:
Policy and Practice Strategies
for Patient Education

Friday, December 6, 2024





Agenda

Friday, December 6, 2024 | 8:30 AM – 3:00 PM EST
National Press Club, Washington, DC

- 8:30 – 9:15 AM **Registration and Breakfast**
- 8:30 AM **Exhibitor Tables Open**
- 9:20 – 9:30 AM **Welcome and Introductions**
Crystal S. Denlinger, MD
Chief Executive Officer
National Comprehensive Cancer Network
- 9:30 – 10:15 AM **Keynote: Engage Every Person: The Importance of Quality Information
for Building Trust in Cancer Research**
W. Kimryn Rathmell, MD, PhD, MMHC
Director, National Cancer Institute
National Institutes of Health
- 10:15 – 10:25 AM **Break**
- 10:25 – 11:40 AM **Panel 1: Building a Supportive Information Ecosystem for Cancer Patients**
Moderated by Clifford Goodman, PhD, Consultant, Health Care Technology and Policy
- Melinda Butsch Kovacic, MPH, PhD
Associate Dean, Professor and Associate Dean of Research
University of Cincinnati
Lead Investigator
We Engage 4 Health
- Dheepa Chari, MS
Vice President, Head of Global Scientific Communications
GlaxoSmithKline
- Martha A. Dawson, DNP, RN, FACHE, FAAN
Immediate Past President
National Black Nurses Association



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Randi C. Ervin
Survivor, Caregiver, & Volunteer
Pancreatic Cancer Action Network

Bryce Reeve, PhD
Professor, Population Health Sciences
Duke University School of Medicine

11:40 AM – 12:40 PM **Lunch**

12:40 – 1:40 PM **Best Practices Presentations: Methods to Improve Patient-Centered Health Information Sharing**

Melinda Butsch Kovacic, MPH, PhD
Associate Dean, Professor and Associate Dean of Research
University of Cincinnati
Lead Investigator
We Engage 4 Health

Lillian Kreppel
Executive Director, Co-Founder along with actress Marcia Cross
Cancer Thriver
HPV Cancers Alliance

Abigail Newell, PhD
Director, Research
Cancer Support Community

Dorothy A. Shead, MS
Senior Director, Patient Information/Operations
National Comprehensive Cancer Network

Amelia Thelin, CHES, ACS LION
Patient Navigator
Frontier & Rural Patient Navigators
Huntsman Cancer Institute at the University of Utah



1:40 – 2:50 PM

Panel 2: Enhancing Access to Accurate Cancer Information

Moderated by Clifford Goodman, PhD, Consultant, Health Care Technology and Policy

Skyler B. Johnson, MD
Professor, Department of Radiation Oncology
Huntsman Cancer Institute at the University of Utah

Tim McDonald
Advocate
FightCRC

Joe Scattergood, MBA
Vice President, Oncology Clinical Trial Enrollment Expansion
Eli Lilly and Company

Arnethea L. Sutton, PhD
Assistant Director of Community Outreach and Engagement
VCU Massey Comprehensive Cancer Center

Robin C. Vanderpool, DrPH
Branch Chief, Health Communication and Informatics Research (HCIRB)
Division of Cancer Control and Population Sciences
National Cancer Institute

2:50 – 3:00 PM

Wrap-up and Conclusion

Wui-Jin Koh, MD
Senior Vice President/Chief Medical Officer
National Comprehensive Cancer Network

Policy Summit Speakers



Melinda Butsch Kovacic, MPH, PhD

Dr. Melinda Butsch Kovacic, MPH, PhD, is a Professor and Associate Dean of Research at the University of Cincinnati's College of Allied Health Sciences. She is also a Professor and the Associate Director of Community Outreach and Engagement at the University of Cincinnati Cancer Center. Her career experiences have spanned the basic sciences, clinical research, population sciences, and public health. As part of her recently completed NIGMS R25 Science Education Program Award (SEPA), she established a 20+ member community-academic partnership later called We Engage 4 Health (WE4H). WE4H iteratively co-created over 80 comic-style stories with community representatives to promote meaningful discussions on health, the environment, and research topics within vulnerable communities. Her current NCI R25 offers 22 undergraduate Cancer Research Scholars opportunities to participate in community outreach using these comic-style stories in addition to doing research in cancer center members' laboratories. Given the success of these efforts, Dr. Butsch Kovacic now encourages and supports numerous faculty members to leverage her established iterative co-design process to co-create new stories for the educational materials associated with their clinics and research.



Dheepa Chari, MS

With over 23 years of experience, Dheepa Chari is a visionary leader that has pioneered new approaches in scientific data communication, digital innovation, and content creation within in the pharmaceutical industry. She currently works as Vice President, Head of Global & US Medical Communications and Content at Pfizer where she leads an organization to drive and execute medical affairs content strategies across publications, congresses, field medical, and digital channels. Prior to this, she served as Global Lead of Oncology Scientific Communications at Pfizer, leading a team to drive omnichannel communications across the oncology portfolio. In this role, her team led the first pilot of abstract plain language summaries in 2018 and the first patient poster track pilot in 2020 at two key global congresses to enable greater transparency of emerging scientific information, both of which have been established as leading industry-first initiatives. Her team was also the first therapeutic area at Pfizer to launch a medical Twitter/X handle focused

on sharing data from peer-reviewed publications. Dheepa has a passion for innovation in data-driven medical communications to drive transformation in disease awareness and patient education.

Prior to these roles, she served as Director of Global Medical Communications at Pfizer Oncology, Scientific Communications Director at Novartis US Oncology, and Global Publication Planning Lead at Amgen. She also worked in clinical study and data management roles at both Amgen and Pfizer across various therapeutic areas including oncology, rare diseases, internal medicine, and inflammation.

Dheepa holds a Master of Science degree in Biostatistics from the Columbia University School of Public Health and a Bachelor of Science degree in Biochemistry with minors in Math and Music from Southern Methodist University. Outside of her pharmaceutical career, Dheepa is a singer & songwriter and performs regularly in NYC.



Martha A. Dawson, DNP, RN, FAAN, FACHE

Martha A. Dawson, DNP, RN, FAAN, FACHE is an Associate Professor at the University of Alabama at Birmingham (UAB) School of Nursing (SON). She is the 13th president of the National Black Nurses' Association. She is the 2024-2025 Chair-Elect of the Nurses on Board Coalition. She earned her bachelor's and master's degrees from the UABSON. In 2010, she earned her Doctor of Nursing Practice from Case Western Reserve University Frances Payne Bolton SON. Dr. Dawson completed her hospital administration residency at Gaston Memorial Hospital, Gastonia NC. Her practice, leadership and scholarship as a translational scientist is in the domains of administrative systematology, career progression, organizational injustices, and anti-racism in nursing. Her work has included a focus on career-mobility barriers, systemic and institutional obstacles. She is a co-convenor of the 2020 National Black Coalition Against COVID that reached over five million during the pandemic. Dr. Dawson was a co-lead on the 2020 National Commission Addressing Racism in Nursing ground breaking work to improve the image and healing within the nursing profession for Black and Brown nurses. She serves on the Advisory Board for Direct Relief Health Equity Fund, Betty Irene Moore Fellows Advisory Board and the UABSON Health Policy Institute.

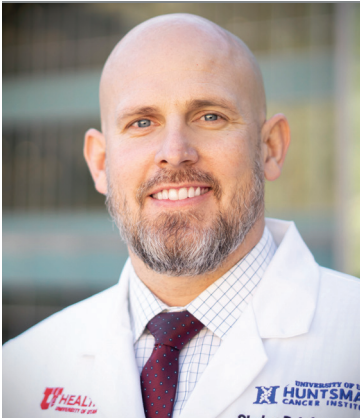
Dr. Dawson's early career centered around health systems administrative leadership. She served in senior level positions such as, Vice President of Clinical Affairs/Operations and Chief Nurse Officer – University of Louisville, Associate Chief Operating Officer – Duke University and Nursing Director of Systems and Finance, and nurse manager at the UAB Medical Center. She managed her own healthcare consultant business. She entered academia in

2008 as an instructor. Dr. Dawson served as the inaugural director of Nursing and Health Systems Leadership track and the coordinator of the Nursing and Health System Administration track. She is a Scholar in the Sparkman Global Health Center at the University of Alabama at Birmingham, an associate scientist in the Social Science and Justice Research Center and a Scholar in the UAB Center for the Study of Community Health, one of 26 Prevention Research Centers designated by the CDC nationally as an interdisciplinary research center. She is a Fellow in the American College of Healthcare Executives, Robert Wood Johnson Nurse Executive Fellow alumina, and a Johnson & Johnson Wharton Nurse Administrative Fellow, alumina. She has served as the principal investigator, project director and coordinator on HRSA and foundation grants exceeding \$5.2 million. In 2004, a mayoral proclamation declared Dr. Dawson a Distinguished Citizen of Louisville, KY. She served as the West Louisville Performing Arts Academy (WLPAA) Board Chair for 6 years and developed the strategic direction to expand the academy to include a girls' choir. She was instrumental in creating a partnership between WLPAA and the University of Louisville to develop a perpetual scholarship program. In 2010, Dr. Dawson received the Madeline R. Zaworski Leadership Award. She was the recipient of the American Organization of Nurse Executives (AONE) Prism Award for Diversity. In 2019, Dr. Dawson was inducted into the Alabama Nurses Hall of Fame, in 2022, named President of the Year by the American Nurses Association and in 2023 listed in Who's Who in American 125th Anniversary Edition. She has publications in books, journals, newsletters and has written op eds.



Randi C. Ervin

Randi was diagnosed with pancreatic neuroendocrine cancer in 2016, and she took on the role of devoted caregiver for her mom, who bravely battled pancreatic ductal adenocarcinoma until her passing in 2023. As a member of the Pancreatic Cancer Action Network's Survivor Council, Randi is deeply involved in advocacy. Having experienced the healthcare system from many angles – patient, caregiver, employee, volunteer, and advocate – she brings a unique and deeply personal perspective on the triumphs of the healthcare system, as well as the challenges of access and navigation.



Skyler B. Johnson, MD

Skyler Johnson, MD is an Assistant Professor in the Department of Radiation Oncology at the University of Utah Huntsman Cancer Institute. As a physician and researcher, he has sought to improve the lives of both individuals and the community through exemplary care and expertise in the area of health services research. His clinical specialties include prostate cancer and other genitourinary malignancies as well as gastrointestinal malignancies, lung cancer, and lymphoma. His research interests include comparative effectiveness, patient communication, patient education, clinical outcomes, quality of life research, cost-effectiveness, decision analyses, and clinical trial design.

Dr. Johnson's research interests and passion for cancer care began during medical school at Michigan State University. He then completed a year-long research fellowship at the University of Michigan in the Department of Radiation Oncology. He completed his residency in radiation oncology at Yale, where he served as Chief Resident. While at Yale, he received additional training as a Health Sciences Research Fellow as part of the Yale National Clinical Scholars Program (NCSP) and a member of the Cancer Outcomes, Public Policy and Effectiveness Research Center (COPPER) group.

His prior comparative effectiveness research on the use of non-traditional cancer treatments garnered national and international media attention from the lay press and resulted in over 450 news stories. He and members of his research team conducted television, radio, and print interviews with NBC, CNN, NPR, BBC, TIME Magazine, Reader's Digest, among others, and it was also prominently featured in the New York Times. More importantly, the research addressed an unmet need in the oncology medical literature and has been used in health policy documents including the WHO's report on cancer. This research has led to ongoing studies in collaboration with national cancer experts quantifying misinformation and potential for harm contained within cancer articles on social media, accuracy of cancer information using AI chatbots, as well as a multi-institutional study identifying sources of exposure, motivations, and perceptions of complementary and alternative medicine use in cancer. Dr. Johnson continually seeks to improve patient care and patient-physician communication by serving as Chair of the Huntsman Cancer Institute's Genitourinary Cancer Centers Communications and Community Outreach Committee as well as being a member of the NRG Oncology New Investigator Committee and American Society for Radiation Oncology's (ASTRO) Communications Committee. He is an internationally recognized expert on cancer misinformation, its impacts, and potential solutions, frequently delivering invited lectures at prestigious institutions across the country and participating in multi-institutional forums on health mis- and disinformation.



Lillian Kreppel

Lillian is the Executive Director, and Co-Founder of HPV Cancers Alliance, along with actress, Marcia Cross and businessman, Dan Lifton. Lillian's personal experience with HPV related anal cancer profoundly influenced her to become an activist and a tireless advocate each and everyday. She knew that she had a responsibility to empower the public and the medical communities through education, awareness and advocacy, and that the time was, and is, NOW. Lillian is motivated, driven and committed to spreading knowledge and saving lives because in her words, "although HPV impacts nearly everyone, no one should die from this preventable virus."



Tim McDonald

Tim McDonald is a stage 4 colon cancer survivor and liver transplant recipient. After receiving his diagnosis, he turned to his pain into purpose and became an advocate. Tim is currently a Research Advocate with Fight CRC. He also volunteers for COLONTOWN and Man Up To Cancer.



Abigail Newell, PhD

Abigail Newell, PhD is a Director of Research at Cancer Support Community (CSC). She received her PhD in sociology from the University of North Carolina at Chapel Hill, where she was an award-winning undergraduate instructor and researcher. Prior to joining CSC, she conducted mixed methods research on four interdisciplinary teams, performed program evaluation for a non-profit dedicated to ending health disparities, and served as an editorial assistant for Social Forces journal. Her research spans a variety of topics, including intersectional health disparities, healthcare policy, and advocacy.

At CSC, Abigail is responsible for designing and conducting mixed methodology research projects on health service delivery, patient and caregiver experiences, quality of life, and health equity. She is passionate about conducting rigorous research to ensure that CSC's programs and education continue to meet the diverse and dynamic needs of patients, survivors, and caregivers. She is excited to be a part of CSC's work increasing cancer patient and caregiver advocacy, awareness, and communication with providers.



W. Kimryn Rathmell, MD, PhD, MMHC

W. Kimryn Rathmell, M.D., Ph.D., M.M.H.C., was sworn in as the 17th NCI director on December 18, 2023. She previously led the Vanderbilt University Medical Center as physician-in-chief and chair of the Department of Medicine.

Dr. Rathmell is a recipient of the 2019 Louisa Nelson Award for Women of Achievement, Vision, and Inspiration, the 2019 Eugene P. Schonfeld Award from the Kidney Cancer Association, and the Paragon Award for Research Excellence from the Doris Duke Foundation. She was a leader of The Cancer Genome Atlas's (TCGA) kidney cancer projects and served as a TCGA analysis working group member across the spectrum of cancers, winning the 2020 American Association for Cancer Research Team Science Award. She has served on the NCI Board of Scientific Advisors, and the Forbeck Foundation Scientific Advisory Board.

Dr. Rathmell has held leadership positions with the American Society of Clinical Oncology and the American Society for Clinical Investigation, serving as secretary-treasurer and president. As a result of her efforts, Dr. Rathmell has been elected to the Association of American Physicians, the American Academy of Arts and Sciences, and the National Academy of Medicine.

Dr. Rathmell's specialty is the research and treatment of complex and hereditary kidney cancers. She also focuses on underlying drivers of kidney cancers using genetic, molecular, and cell biology to develop interventions to improve patients' lives. Dr. Rathmell's research has resulted in more than 250 articles in leading peer-reviewed journals, including The New England Journal of Medicine, Nature, Proceedings of the National Academy of Sciences, and the Journal of Clinical Investigation.

Dr. Rathmell earned undergraduate degrees in biology and chemistry from the University of Northern Iowa and her Ph.D. in biophysics and M.D. from Stanford University. She completed an internal medicine internship at the University of Chicago and an internal medicine residency, medical oncology fellowship, and postdoctoral studies at the University of Pennsylvania. In 2022, she completed her Master of Management in Health Care from the Vanderbilt University Owen Graduate School of Management.



Bryce Reeve, PhD

Dr. Bryce Reeve is a Professor of Population Health Sciences and Professor of Pediatrics at Duke University School of Medicine. He also serves as Director of the Center for Health Measurement since 2017. Trained in psychometric methods, Dr. Reeve's work focuses on assessing the impact of disease and treatments on the lives of pediatric and adult patients and their caregivers. This includes the development of clinical outcome assessments using both qualitative and quantitative methods, and the integration of patient-centered data in research and healthcare delivery settings to inform decision-making. From 2000 to 2010, Dr. Reeve served as Program Director for the U.S. National Cancer Institute and oversaw a portfolio of health-related quality of life research in cancer patients. From 2010 to 2017, he served as Professor of Health Policy and Management at the University of North Carolina. From 2011-2013, Dr. Reeve served as President of the International Society for Quality of Life Research (ISOQOL). In 2015, he received the John Ware and Alvin Tarlov Career Achievement Prize in Patient-Reported Outcomes Measures. In 2017, 2018, 2019, 2021, 2022, and 2023, he was ranked in the top 1% most-cited in his respective field over the past 11-year period.



Joe Scattergood, MBA

Joe currently leads a business-wide effort at Lilly focused on broadening oncology clinical trial enrollment in the US. His team is working to expand the scope of enrollment-driving activity beyond Lilly's clinical development teams and applying Commercial and Medical Affairs principles and toolkits, as well as optimizing internal processes and procedures related to oncology clinical trial execution and evaluating and piloting new technology innovations.

Joe joined Loxo Oncology in 2017 (acquired by Lilly in 2019) where he has held roles in Marketing (Vitrakvi and Jaypirca), Operations, Alliance Management, Integration, Organizational Strategy and R&D Program Management. Prior to Lilly and Loxo, he worked in US and global oncology marketing at Pfizer and AbbVie on the launch teams for Xalkori, Ibrance, and Venclexta, among others. Prior to that, Joe was a pricing & reimbursement consultant for IMS Health (now IQVIA) and a research assistant at MSKCC. He holds a BA from Brown and an MBA from Wharton.



Dorothy A. Shead, MS

Dottie is the Senior Director of Patient Information Operations at The National Comprehensive Cancer Network® (NCCN®), a not-for-profit alliance of 33 of the world's leading cancer centers devoted to patient care, research, and education, is dedicated to improving the quality, effectiveness, and efficiency of cancer care so that patients can live better lives. Dottie is a passionate healthcare leader with extensive expertise in the development of the NCCN Guidelines, and implementation of health literacy, diversity, language services, patient education, and engagement best practices. She has over 20 years of experience with NCCN, working on both the NCCN Clinical Practice Guidelines in Oncology and the NCCN Guidelines for Patients. In her current role, Dottie oversees the development of all patient/consumer education initiatives in oncology.



Arnethea L. Sutton, PhD

Dr. Arnethea Sutton is an assistant professor in the Department of Kinesiology and Health Sciences and an affiliate faculty in the Department of Social and Behavioral Sciences at Virginia Commonwealth University. She also serves as an Assistant Director of Community Outreach and Engagement at VCU Massey Comprehensive Cancer Center. She is a trained community-engaged and cancer disparities researcher, receiving her training through a National Cancer Institute (NCI) funded T32 program in cancer prevention control. In her role as assistant director, Dr. Sutton oversees outreach efforts focused on engaging faith communities and facilitating screening and navigation throughout Massey's catchment. Regarding the former, Dr. Sutton leads Facts and Faith Fridays (FFF), a four-year partnership between approximately 150 Black/African American churches. FFF serves to 1) provide accurate and timely health information to the faith leaders and their respective communities, 2) facilitate community-engaged research, including clinical trials, and 3) advocate for policies relevant to cancer and social drivers of health (e.g., colorectal cancer screening, housing). Dr. Sutton has expertise in employing community-engaged approaches in research focused on addressing racial disparities in breast cancer prevention and survivorship. Currently, Dr. Sutton is the Principal Investigator of the Cancer Advocacy and Research for Equity in Survivorship (CARES) Lab. The CARES lab, funded in part by a National Cancer Institute K99/R00, is guided by a community advisory board (CAB) of five breast cancer survivors who contribute to every research project from idea formation to dissemination. Dr. Sutton currently serves on various professional and community boards and committees. She is the chair of the cancer disparities special interest group of the American Society of Preventive Oncology, an assistant editor for JACC: Cardiooncology, and she serves on the Board of Directors for Here for the Girls and on the Medical Advisory Board for the Tigerlily Foundation.



Amelia Thelin, CHES, ACS LION

Amelia Thelin is the Frontier/Rural Patient Navigator at Huntsman Cancer Institute (HCI). In this role Amelia serves patients from Montana, Wyoming, and rural Utah, helping them overcome barriers to care, access resources and information, and navigating them through complex healthcare systems. She is coinvestigator on the Innovations in Rural Oncology Navigation research project underway at HCI, and is frequently sought out as a resource in understanding the rural oncology patient experience.

Amelia's upbringing on a farm in rural eastern Washington provides unique insight into the challenges that rural patients face, and the cultural nuances often overlooked in healthcare. She holds a bachelor's degree in public health and human services from Brigham Young University – Idaho, complemented by certifications in Health Education and Patient Navigation. Amelia's extensive background in public education, particularly with special education students and families across diverse regions, underscores her commitment to community support. Passionate about health equity, Amelia bridges connections between healthcare systems, advocating for improved access to cancer care for underserved populations in rural areas. Her role is instrumental in navigating the complexities of the healthcare system and ensuring patients receive comprehensive support throughout their cancer journey.



Robin C. Vanderpool, DrPH

Robin C. Vanderpool, DrPH is chief of the Health Communication and Informatics Research Branch at the National Cancer Institute (NCI) where she leads a team dedicated to the development of research initiatives in areas such as cancer communication surveillance, patient-centered communication, digital health, and online health information. Dr. Vanderpool also collaborates with the Cancer Information Service, an essential part of NCI's information dissemination efforts as well as the NCI Office of Cancer Centers on catchment area, rural cancer control, and community outreach initiatives.

Prior to joining NCI, Dr. Vanderpool was a professor in the College of Public Health at the University of Kentucky (UK) and associate director for community outreach and engagement at the UK Markey Cancer Center.

Dr. Vanderpool earned a DrPH in Health Behavior from UK (2006); a MPH in Public Health Education from Western Kentucky University (1999); and a BS in Psychobiology from Centre College (1997).



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