



National  
Comprehensive  
Cancer  
Network®

# JNCCN

JNCCN.org

Journal of the National Comprehensive Cancer Network

## **The Alliance for Quality Psychosocial Cancer Care: An Innovative Model for Disseminating and Improving Implementation of National Quality Care Recommendations**

**Ruth McCorkle, Rebecca Kirch, Kim Thiboldeaux, Julie Taylor and Mark Gorman**

*J Natl Compr Canc Netw* 2014;12:947-951

Copyright © 2014 by the National Comprehensive Cancer Network. All rights reserved.  
Print ISSN: 1540-1405. Online ISSN: 1540-1413.

*JNCCN – The Journal of the National Comprehensive Cancer Network* is published by  
Harborside Press, 37 Main Street, Cold Spring Harbor, NY 11724

---

<b>Online article</b>	<a href="http://www.jnccn.org/content/12/6/947.full">http://www.jnccn.org/content/12/6/947.full</a>
<b>Subscriptions</b>	Information about subscribing to <i>JNCCN – The Journal of the National Comprehensive Cancer Network</i> is online at <a href="http://www.jnccn.org/site/subscriptions/">http://www.jnccn.org/site/subscriptions/</a>
<b>Permissions</b>	For information about photocopying, republishing, reprinting, or adapting material, please go online to <a href="http://www.NCCN.org/permissions">http://www.NCCN.org/permissions</a>

---

NCCN.org



## The Alliance for Quality Psychosocial Cancer Care: An Innovative Model for Disseminating and Improving Implementation of National Quality Care Recommendations

Ruth McCorkle, PhD; Rebecca Kirch, JD; Kim Thiboldeaux; Julie Taylor; and Mark Gorman

In 2008, the Cancer Support Community and the American Psychosocial Oncology Society joined forces to bring together key professional and advocacy stakeholders from the cancer and mental health communities to form the Alliance for Quality Psychosocial Cancer Care. The Alliance was formed in response to the 2007 Institute of Medicine (IOM) report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*,<sup>1</sup> and its specific emphasis on implementing a standard for quality cancer care that includes providing appropriate psychosocial health services by:

- Facilitating effective communication between patients and care providers;
- Identifying each patient's psychosocial health needs; and
- Designing and implementing a plan that links the patient with needed psychosocial services, coordinates biomedical and psychosocial care, engages and supports patients in managing their illness and health and in systematically following up on, reevaluating, and adjusting plans.

The report was the result of funding appropriated to the Department of Health and Human Services (HHS) to study (1) the capacity of the current mental health and oncology provider system to deliver psychosocial services to individuals with cancer and their family members; (2) available training programs for professionals providing psychosocial and mental health services; and (3) the existing barriers to access to cancer-related mental health services. The IOM report highlights the critical need to improve awareness among clinicians and consumers about the importance of integrating psychosocial care in oncology treatment, to identify national and community resources currently available supporting delivery of this integrated quality care, and to expand or enhance existing programs and services to meet the social and emotional needs of all people facing cancer and its aftermath.

The Alliance was formed to give life to the report's recommendations on the frontlines of practice, pulling together key stakeholder organizations and others with a shared interest in advancing integration of psychosocial care into the medical standard of care for people with cancer. The Alliance now includes more than 30 member organizations (Table 1), reflecting a diverse cross-section of groups and individuals representing community services, clinical care providers, patient advocates, and researchers. Together, the Alliance membership offers a collective, collaborative voice and information-sharing forum for coordinating plans and taking strategic action.

As the Alliance was being formed, its founders worked to carefully define its unique role (Table 2) with the goal of retaining focus while avoiding duplication of efforts among member organizations (Table 3). Carol Alter, MD, Director of Psychosomatic Medicine, Policy and Outreach, at Georgetown University Hospital, played a key leadership role in the formation of the Alliance. Dr. Alter was instrumental in bringing together a steering committee to clarify the Alliance's purpose and objectives, formulate committees to carry out its work, and oversee its initial activities. Through her leadership, the Alliance evolved quickly into its current structure and role as a convener of organizations committed to raising awareness about



**Ruth McCorkle, PhD**

Ruth McCorkle, PhD, is the first Florence Schorske Wald Professor at Yale School of Nursing and a Professor in the Department of Epidemiology and Public Health at Yale School of Medicine. She also has served as the program leader for Cancer Control at the Yale Comprehensive Cancer Center (YCCC) and is currently the Director of the Psychosocial Oncology Research Program at Smilow Cancer Hospital of YCCC. Dr. McCorkle received a bachelor's degree in nursing from the University of Maryland, a master's in medical-surgical nursing from the University of Iowa, and a doctorate in mass communication, from the University of Iowa's School of Journalism.

Some of Dr. McCorkle's many honors include a Distinguished Merit Award from the International Society of Nurses in Cancer Care, a Distinguished Research Award from the Oncology Nursing Society, and being named the Nurse Scientist of the Year by the Council of Nurse Researchers of the American Nurses Association. She received the Bernard Fox Research Award for outstanding contribution to the field of Psychooncology and the Jimmie Holland award for distinguished leadership from the American Psychosocial Oncology Society. A prolific writer, her work appears in many professional journals in the United States and abroad.

The ideas and viewpoints expressed in this commentary are those of the author and do not necessarily represent any policy, position, or program of NCCN.

McCorkle et al



### Rebecca Kirch, JD

Rebecca Kirch, JD, is the American Cancer Society's Director of Quality of Life & Survivorship. Based in Washington, DC, she provides strategic direction and coordination for the Society's national agenda addressing quality care and quality of life issues for all adults and children facing cancer and its aftermath. Through research, programs, and advocacy, these initiatives include a suite of policies and practices that integrate palliative care for managing pain, symptoms, and stress; psychosocial care for emotional support; and impairment-driven rehabilitation for addressing disability and enhancing person-centered and goal-directed clinical communication skills. Ms. Kirch's efforts were honored with the Center to Advance Palliative Care's 2013 Innovation Award and a 2011 Presidential Citation to the Society from the American Academy of Hospice & Palliative Medicine. Her achievements in the national pain policy arena were recognized earlier with the American Academy of Pain Management's Legislative Policy and Advocacy Award. She has a law degree from Boston College Law School and an undergraduate degree in Biology from Wells College.

**Table 1 Alliance for Quality Psychosocial Cancer Care Member Organizations**

Academy of Psychosomatic Medicine	Dana-Farber Cancer Institute
American Academy of Pain Management	International Psycho-oncology Society
American Cancer Society	Kidney Cancer Association
American Childhood Cancer Organization	The Leukemia & Lymphoma Society
American Psychiatric Association	The LIVESTRONG Foundation
American Psychosocial Oncology Society	Lung Cancer Alliance
American Psychosomatic Society	National Association of Social Workers
American Society of Clinical Oncology	National Coalition for Cancer Survivorship
American Society for Radiation Oncology	Free to Breathe (formerly National Lung Cancer Partnership)
Association of Community Cancer Centers	National Patient Advocate Foundation
Association of Oncology Social Work	Robert H. Lurie Comprehensive Cancer Center of Northwestern University
Association of Pediatric Oncology Social Workers	Society of Behavioral Medicine
CancerCare	UC Irvine Health Chao Family Comprehensive Cancer Center
Cancer Legal Resource Center	University Hospitals Seidman Cancer Center
Cancer Support Community	Yale Cancer Center
Center for Advancing Health	
Center for Communication in Medicine	

the importance of psychosocial care and the importance of integrating these services as a standard of quality cancer care. Because of Dr. Alter's efforts, Alliance leadership evolved to its current structure, led by cochairs Ruth McCorkle, PhD, American Psychosocial Oncology Society; Kim Thiboldeaux, Cancer Support Community; and Mark Gorman, National Coalition for Cancer Survivorship. Rebecca Kirch, JD, American Cancer Society, joined as cochair in 2012, on Mr. Gorman's retirement. These cochairs represent the key constituencies of Alliance member organizations—research, community services, clinical care, and advocacy. Alliance initiatives are undertaken by 3 committees: Best Practices, Education and Awareness, and Public Policy and Advocacy (Table 4).

The Alliance has defined its role as:

- Serving as a convener and facilitator across stakeholder members to create and sustain momentum for activities implementing recommendations from the IOM report;
- Organizing and keeping members informed of activities among member organizations;
- Facilitating collaboration when appropriate and avoiding duplication when possible;
- Developing key messages regarding quality psychosocial cancer care as a standard and coordinating consistent and strategic delivery of messages by member organizations;

**Table 2 Purpose of the Alliance**

- Convene key stakeholders committed to implementing the recommendations of the IOM report, "*Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*"
- Inform and educate key audiences that quality psychosocial care is critical to optimal clinical outcomes for people affected by cancer
- Advocate policies to ensure that all patients are screened and have access to quality psychosocial care
- Advance translational research and standards of care in psychosocial oncology

## Alliance for Quality Psychosocial Cancer Care

- Formulating letters, statements, and other appropriate communication materials for member endorsement to ensure consistent messages to help influence legislative, regulatory, standards-setting, and other policy initiatives; and
- Informing members of potential funding opportunities that will facilitate integration of psychosocial services as the standard of care.

## Governance

Although the Alliance does not have a formal charter, careful thought was given to its structure and function. Since its inception, the Alliance has functioned as a “coalition of the willing.” A modest budget from member contributions is used to pay one staffing consultant to organize and facilitate coalition activities, and to cover associated administrative costs. Under this structure, one member organization serves as the fiduciary agent. Alliance activities are guided by the cochairs and driven by the work of the committees and membership at large. Most work is performed via phone and email, but the cochairs also meet regularly in person. In addition, the membership participates in regular conference calls to provide reports on membership activities and committee initiatives. These calls also feature a guest speaker on a topic of interest, typically suggested by members, that serves to further the work of the Alliance in raising awareness and advocating for the integration of psychosocial cancer care.

## Making a Difference

Shortly after its formation, IOM leadership recognized the Alliance as a first-of-its-kind dedicated effort that could serve as an innovative model for translating the recommendations of future IOM reports into action. In the years since its inception, the Alliance’s activities have contributed significantly in raising awareness and improving understanding about the importance of integrating psychosocial services to address the social and emotional needs of those impacted by cancer. Highlights include:

- A Web site was created with a searchable database of more than 750 state, regional, and national resources to help address the psychosocial needs of patients, survivors, and caregivers ([www.wholecancerpatient.org](http://www.wholecancerpatient.org)).
- A “Resource Guide” was compiled for Commission on Cancer (CoC)–accredited facilities, to share services, programs, and examples of best practices from Alliance members, to help them meet the CoC’s new patient-centered standards for cancer programs. The Guide, disseminated in March 2014, contains 2 companion documents and is available at <http://www.cfah.org/about/alliance-for-quality-psychosocial-cancer-care> under the “Resources” heading.
- Materials are developed, including social media messages, PowerPoint presentations, and talking points, for organizations to raise awareness among their respective constituencies.

**Table 3 Member Organization Roles**

- Serve as drivers, advocates, and leaders in implementing the standard of care based on their respective expertise and organizational position, etc
- Actively participate as stakeholder in at least one of the Alliance committees
- Advance specific projects or initiatives for which they are uniquely positioned to develop and fund and communicate to membership about these activities
- Seek partnership and collaboration from Alliance membership when appropriate
- Deliver messages and advance collaborative communication strategies developed by the Alliance to raise psychosocial care awareness and understanding



### Kim Thiboldeaux

Kim Thiboldeaux joined The Wellness Community in 2000 as President and CEO, a role she maintained when the headquarter offices of The Wellness Community and Gilda’s Club joined forces to become the Cancer Support Community in 2009. The Cancer Support Community provides social and emotional support through a network of more than 50 local affiliates, more than 100 satellite locations, and online at [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org). Formerly the Director of Patient Relations for Oncology & Transplant at Hoffmann-LaRoche, Inc., Ms. Thiboldeaux has experience in health care, patient education, and national patient advocacy. She serves in numerous leadership roles in the cancer and health care communities, including member of the American College of Surgeons Commission on Cancer, Cochair of the Alliance for Quality Psychosocial Care, Advocacy Board Member of the Ruesch Center for the Cure of GI Cancers at Lombardi Comprehensive Cancer Center, and Cancer Today magazine National Advisory Board Member. Ms. Thiboldeaux is the coauthor of *Reclaiming Your Life After Diagnosis* (2012) and *The Total Cancer Wellness Guide* (2007), and the host of “Frankly Speaking About Cancer” with the Cancer Support Community, an award-winning Internet talk radio show that airs weekly on [VoiceAmerica.com](http://VoiceAmerica.com) and is aimed at informing and inspiring listeners to live well with cancer.



McCorkle et al



### Julie Taylor

Julie Taylor serves as the administrator for the Alliance for Quality Psychosocial Cancer Care. She is a project consultant to numerous organizations including the Cancer Support Community. Prior to her work with CSC and the Alliance, she worked as Director of Cancer Policy for ASCO.

**Table 4 Objectives of the Committees of the Alliance**

**Education and Awareness**

Develop a plan to inform oncology and psychosocial providers, patients, and others on the findings and recommendations of the report; help compile presentations that can be used in a variety of settings

**Best Practices**

Identify and disseminate best practices of distress screening and psychosocial services through implementation of quality standards and research

- promote adoption of quality standards for psychosocial care of patients with cancer throughout the continuum of cancer care
- identify and disseminate best practices for psychosocial care (screening, referral, and follow-up)
- promote psychosocial care research and the integration of quality standards into practice
- promote adoption of standards for psychosocial care of patients with cancer

**Public Policy and Advocacy**

Advocate for policies and practices to ensure that all patients undergo screening for psychosocial care needs and have access to quality psychosocial care

The Alliance was an influential force in developing and supporting the American College of Surgeon's proposal, through its CoC, of the new patient-centered standard promoting routine distress screening in oncology care as a component of facility accreditation. This standard was approved as part of the CoC's 2012 "Ensuring Patient-Centered Care" program standards, which require cancer committees at more than 1500 CoC-accredited hospitals, free-standing cancer centers, and cancer program networks nationwide to develop and implement a process for integrating and monitoring on-site psychosocial distress screening and referral for the provision of psychosocial care by 2015.

In addition, a bibliography with summaries of key journal articles on psychosocial screening compiled by the Best Practices Committee continues to grow as new articles are published. The Policy and Advocacy Committee has worked to ensure that legislative proposals incorporate language addressing psychosocial care needs and integrate meeting these needs into the standard of care. The Alliance has also submitted comments to the ASCO/Oncology Nursing Society Standards for Safe Chemotherapy Administration to support relevant references to psychosocial care. The Alliance has presented at professional meetings, including at the 2011 American Psychosocial Oncology Society Annual Conference and the 2010 Sixth World Conference on the Promotion of Mental Health and Prevention of Mental and Behavioral Disorders. The Alliance also submitted a letter to the IOM National Cancer Policy Forum urging inclusion of policies that implement the recommendations of the Cancer Care for the Whole Patient report in its future work and policy proposals.

### Moving Forward

As the Alliance moves from the "start-up" phase to focusing more on implementation and evaluation, enhancing engagement of member organizations through the quarterly call series and information exchange will continue. We will strengthen efforts to communicate broadly among multiple audiences about the importance of screening for distress and providing quality care based on screening findings. At the same time, the Alliance will work collaboratively across its membership and through its committees to support institutional efforts to develop comprehensive psychosocial care plan/programs by helping identify what resources are needed and which are already available for referral and intervention. To help accomplish these objectives, we will continue to build on the Resource Guide for services, programs, and best practices

## Alliance for Quality Psychosocial Cancer Care

examples and to promote awareness of the Guide to CoC-accredited institutions and others. The Alliance is also working to continually improve the database and other content on its Web site ([www.wholecancerpatient.org](http://www.wholecancerpatient.org)).

The Alliance has built and sustained a membership of more than 30 committed and active organizations over 5 years. Feedback from members and other organizations has confirmed that the collaborative efforts of the Alliance contributed significantly to furthering the goals and recommendations of the IOM report. In this time of health reform and increasing emphasis on the critical role of psychosocial care to meet the social and emotional needs of the patient, the Alliance is committed to raising awareness and helping organizations and institutions fulfill their missions of providing quality cancer care for all.

To learn more about the Alliance and advocating for psychosocial screening and management of cancer-related distress, contact Julie Taylor at [jtaylor@cancersupportcommunity.org](mailto:jtaylor@cancersupportcommunity.org).

## References

1. Adler NE, Page AE, eds. Institute of Medicine Report: Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. Washington, DC: National Academies Press; 2008.
2. American College of Surgeons. Commission on Cancer Program Standards 2012, Version 1.2.1: Ensuring Patient-Centered Care. Chicago, IL: American College of Surgeons; 2011.



### Mark Gorman

Mark Gorman is a cancer survivor and patient advocate. He is a past cochair for the Alliance for Quality Psychosocial Cancer Care and former Director of Survivorship Policy for the National Coalition for Cancer Survivorship.