



Promoting Research in Oncology Social Work

**A White Paper from the
Association of Oncology Social Work
Post-Conference Research Institute**

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AOSW Research Committee

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Letter from the Research Institute Co-chairs

Dear Colleagues,

On behalf of the Research Committee of the Association of Oncology Social Work (AOSW), we are pleased to present this report, *Promoting Research in Oncology Social Work: A White Paper from the Association of Oncology Social Work Post-Conference Research Institute*. The AOSW is a nonprofit international organization dedicated to the enhancement of psychosocial services to people with cancer, their families and caregivers. Robust research activities are necessary to achieve this goal. In May 2016, a Research Institute was held following the AOSW Annual Conference. This was the first-ever activity bringing oncology social workers, researchers, and students together to advance research in oncology social work.

Psychosocial care is defined as the “psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health.”¹ Current research documents the positive effects of psychosocial care for cancer patients and their families in terms of enhanced patients outcomes, medical cost-offsets, and even survival.

As the primary providers of psychosocial care, oncology social workers are trained and well positioned to influence cancer care delivery by contributing to the generation, dissemination, and implementation of evidence to inform patient-centered care. Now more than ever, oncology social worker perspectives and contributions to research are needed to address the known shortcomings and disparities in the delivery of psychosocial support services to those who need them. Our evidence base becomes stronger and more relevant when social workers are involved as both producers and consumers of research.

In establishing a research institute, our goal is to develop a sustainable community of oncology social work practitioners and social work researchers devoted to assuring the delivery of high-quality cancer care for all patients and their families. Our intention is to build off of the success of the Association of Oncology Social Work Project to Assure Quality Cancer Care (APAQCC) and establish a patient-centered research cooperative group (PCRCG) for psychosocial oncology. A PCRCG will significantly increase opportunities for influencing the quality of cancer care. It will provide an infrastructure for involving AOSW members in patient-centered research,

¹ Institute of Medicine. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington, DC: National Academies Press; 2008.

establishing best practices for oncology social work, and eliciting systems changes necessary for enhancing patient and family care.

Initiatives that educate all providers on the provision of psychosocial care are needed, as are ongoing efforts to evaluate oncology social work's contributions to improving patient experiences of care, improving health of populations, and reducing the costs of care. In responding to new quality-care initiatives and an emerging emphasis on patient-centered and value-based care, our profession is again challenged to work across professional disciplines and change systems of care to improve the health and welfare of both patients with cancer and their families. We have an opportunity to infuse this work with the professional and patient-centered values of the social work profession, ones that emphasize and promote self-determination, empowerment, and social justice.

This White Paper provides some background on recent developments in oncology social work research and an overview of the Research Institute, including identification of its major themes and suggested next steps. We hope you find the information in this White Paper useful to you.

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Background

Nearly 1.7 million people² will be diagnosed with cancer in the United States in 2016, a number that is expected to rise in the years ahead as the population ages. At the same time, earlier diagnosis and more effective treatments have helped reduce the overall cancer mortality rate. These trends translate into a rising number of cancer survivors: It is estimated that there are 15.5 million individuals³ in the United States who are currently living after a cancer diagnosis—individuals who are cured, in remission, or living with the disease—up from 7 million in 1992. That number is predicted to increase by 31% by 2026, to nearly 20 million. Furthermore, physical and behavioral health outcomes vary across subgroups of the US population, such as race/ethnicity, socioeconomic status, gender identity, and sexual orientation. Disparities exist, and sometimes it is the most vulnerable subpopulations that carry a disproportionate burden.

This growing and diverse population of people diagnosed with cancer, many of whom are living longer with the disease, faces myriad challenges, ranging from acute and long-term medical issues, to emotional distress, to workplace concerns. In addition, other trends in medicine and cancer care have added to the complexity of the psychosocial needs of patients and family members, including the shifting of treatment to outpatient settings and the rising responsibility of patients and families for managing care. Many cancer patients and their families also experience “financial toxicity,” a combination of financial stress, anxiety, and depression, resulting from costlier and longer regimens and ever-greater out-of-pocket costs that outstrip their ability to pay for needed care.⁴

Over the past four decades, the field of oncology social work has grown and evolved⁵ in concert with these massive shifts in cancer care, as social workers stepped up efforts to help address the psychosocial needs of people with cancer and their families. During this period of evolution, certain developments helped drive the field and shape the work of oncology social work practitioners and researchers.

The National Comprehensive Cancer Network (NCCN) developed the concept of cancer-related “distress” and published its first guidelines for distress management in 1999. (In its latest version

² <http://www.cancer.gov/about-cancer/understanding/statistics> (Accessed July 16, 2016)

³ <http://cancercontrol.cancer.gov/ocs/statistics/statistics.html> (Accessed August 19, 2016)

⁴ Zafar SY. Financial Toxicity of Cancer Care: It’s Time to Intervene. *J Natl Cancer Inst.* 2015;108(5):djv370–4. doi:10.1093/jnci/djv370.

⁵ Hedlund S. Oncology social work: Past, present, and future. In GH Christ, C Messner, L Behar (eds.), *Handbook of Oncology Social Work: Psychosocial Care for People with Cancer*. New York, NY: Oxford University Press; 2015:9-13.

of the guideline, the NCCN defines “distress” as the “multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment.”⁶ The NCCN also developed the Distress Thermometer, an instrument to measure distress, and advised performing distress screening in all clinical settings for those with a history of cancer. But a 2007 study⁷ of NCCN member institutions that treated adults with cancer found that only three of the country’s 18 top cancer centers surveyed were routinely performing distress screening on all patients and their families.

A landmark report, published in 2008 by the Institute of Medicine (now called the Academy of Medicine, part of the National Academies of Sciences, Engineering, and Medicine), *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*,⁸ provided a major stimulus in advancing the conversation about these issues. The report noted that there was sufficient evidence to support the provision of psychosocial health services in cancer care to all patients who needed them. Meeting this standard of care, the IOM committee noted, included acting to identify each patient’s psychosocial health needs; designing and putting into place a plan that links the patient with needed services and coordinates biomedical and psychosocial care; and systematically following up and adjusting plans, as needed. However, for many patients with cancer, this standard of care was not being met.

In addition, the IOM report included a recommendation about research priorities,⁶ calling on organizations sponsoring research in oncology care to include as funding priorities “tools and strategies for use by clinical practices to ensure that all patients with cancer receive care that meets the standard of psychosocial care.” Such tools and strategies include approaches for improving patient-provider communication and providing decision support to patients, screening instruments for identifying patients with a constellation of psychosocial health problems, approaches for effectively linking patients with services and coordinating care, and the development of standard outcome measures for assessing the effectiveness of services provided.

Building on the NCCN guidelines and the IOM report, the American College of Surgeons Commission on Cancer, which reviews and accredits more than 1,500 American cancer centers, issued a mandate on distress screening. It required centers to have protocols in place by January 2015 to screen and identify patients experiencing distress and to refer them, when appropriate,

⁶ https://www.nccn.org/professionals/physician_gls/pdf/distress.pdf (Accessed July 16, 2016)

⁷ Jacobsen PB, Ransom S. Implementation of NCCN distress management guidelines by member institutions. *J Natl Compr Canc Netw*. 2007;5(1):99-103.

⁸ Institute of Medicine. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington, DC: National Academies Press; 2008.

for psychosocial care. As a condition of accreditation, centers must provide evidence that distress screening protocols are carried out as intended and result in appropriate referral and follow-up when indicated. The Commission on Cancer mandate galvanized psychosocial providers, including social workers, to begin to screen patients for distress. It also spurred researchers to study the implementation of distress screening in the clinical setting to help the profession manage this new requirement.

Among the responses of oncology social work researchers to these important changes has been the Association of Oncology Social Work Project to Assure Quality Cancer Care (APAQCC), an effort initiated in 2014 to gather data across cancer centers to assess their capacity to deliver psychosocial support services, in particular distress screening. (For a more detailed discussion of distress screening, see “Clinical data-mining as a practice-based research strategy for oncology social workers.”) In addition, the November 2012 issue of the *Journal of Psychosocial Oncology*, the official journal of the Association of Oncology Social Work (AOSW), focused on the theme of “Distress Screening: Approaches and Recommendations for Oncology Social Workers.”⁹ Researchers also conducted a national survey of AOSW members about their experience with distress screening, finding that although social workers reported high screening implementation rates, they encountered “important institutional and individual barriers to their efforts,” such as lacking a protocol or procedure for implementing distress screening, or seeing patients only at the time of first diagnosis, when nearly all are distressed.¹⁰ Finally, to build on these earlier ventures, the AOSW launched the inaugural Post-Conference Research Institute, to help oncology social workers play a more active role in research and data collection, analysis, interpretation, and dissemination.

“Since the inception of oncology social work practice three decades ago, social workers have been at the forefront of efforts to identify and meet the psychosocial needs of cancer patients and their families,” noted Edwina Satsuki Uehara, PhD, MSW, of the School of Social Work, University of Washington, in Seattle, in the *Handbook of Oncology Social Work: Psychosocial Care for People with Cancer*.¹¹ As practitioners who are focused on patient-centered approaches to care and are the primary providers of psychosocial care for people living with cancer, social workers have much to offer in contributing to the evidence base for practice that supports the health and well-being of cancer patients and their families.

⁹ Available at <http://www.tandfonline.com/toc/wjpo20/30/6> (Accessed July 16, 2016)

¹⁰ BrintzenhofeSzoc K, Davis C, Kayser K, Lee HY, Nedjat-Haiem F, Oktay JS, Zabora J, Zebrack BJ. Screening for Psychosocial Distress: A National Survey of Oncology Social Workers. *J Psychosoc Oncol*. 2015;33(1):34-47. doi:10.1080/07347332.2014.977416

¹¹ Uehara, ES. Preface. In GH Christ, C Messner, L Behar (eds.), *Handbook of Oncology Social Work: Psychosocial Care for People with Cancer*. New York, NY: Oxford University Press; 2015: xiii.

The AOSW Post-Conference Research Institute: Rationale and Agenda

The Association of Oncology Social Workers (AOSW) held its first two-day Post-Conference Research Institute on May 6–7, 2016, immediately following the AOSW’s 32nd Annual Conference in Tampa, Fla.

Oncology social workers have long served as front-line advocates of caring for the “whole patient,” through incorporating psychosocial care into the treatment of patients with cancer and promoting patient- and family-centered care.¹² Social work also has a long tradition of research; a key component of the field’s mission is promoting reliance on research findings to inform psychosocial care and generating new knowledge through academic and practice-based research.

Now oncology social workers are poised to assume a more prominent role in research, enriching the evidence base for practice that addresses the needs of cancer patients and their families. This shift has been driven, in part, by the publication of influential reports that heightened the visibility of social work’s role in care of the whole patient, by actions of accrediting bodies and US health agencies that address patient-centered care, and by research from oncology social workers that underscores their leadership role in addressing the psychosocial needs of cancer patients and their families.

- Publication of *From Cancer Patient to Cancer Survivor: Lost in Transition*, a 2006 report from the Institute of Medicine (IOM), which prompted cancer centers around the country to begin developing survivor clinics, often led by oncology social workers, “as they understood the psychosocial implications of survivorship.”¹³
- Widespread attention garnered by the 2008 IOM report *Cancer Care for the Whole Patient: Meeting Psychosocial Needs*, which forcefully advocated that psychosocial care should be integrated as an essential component of cancer care, a longstanding practice of oncology social workers.

¹² Hedlund, S. Oncology social work: Past, present, and future. In GH Christ, C Messner, L Behar (eds.), *Handbook of Oncology Social Work: Psychosocial Care for People with Cancer*. New York, NY: Oxford University Press; 2015:9-13.

¹³ Day, K. Meeting psychosocial health needs: An Institute of Medicine report comes to life. In GH Christ, C Messner, L Behar (eds.), *Handbook of Oncology Social Work: Psychosocial Care for People with Cancer*. New York, NY: Oxford University Press; 2015:27-31.

- A mandate for distress screening and referral of patients for psychosocial care when appropriate, by the American College of Surgeons Commission on Cancer, as a condition for accreditation.
- The passage of the Affordable Care Act, which includes provisions that place more attention on patient-centered care, including linking payment for value-based care to achieving (along with better health and lower costs) better patient experience as measured by “patient satisfaction.” As this shift from volume-based care to value-based care progresses, “achieving the highest levels of quality will depend on how well mental health and behavioral health providers are integrated into the medical care systems and enabled to enhance patient outcomes as well as operational efficiencies and cost offsets.”¹⁴
- The AOSW’s Project to Assure Quality Cancer Care (APAQCC), an effort initiated in 2014 to assess the capacity of cancer programs to provide quality psychosocial support and implement distress screening across cancer programs.¹⁵

The AOSW Post-Conference Research Institute is an effort that grew out of the recognition that these forces have set the stage to foster a stronger research agenda for the field and to bridge the gap between research and practice. Supported with funding from Medivation and Genentech, the Research Institute was conceived as a venue for researchers, including established leaders in the field, and oncology social work practitioners interested in conducting research, to meet others with similar interests and to facilitate mentorship.

“I see the Post-Conference Research Institute as an attempt to build on these earlier ventures, to ultimately move research into a critical position for this rapidly developing field,” said AOSW research director Julianne S. Oktay, PhD, MSW, of the University of Maryland. The Research Institute was led by Dr. Oktay, chair, and by co-chair Brad Zebrack, PhD, MSW, MPH, of the University of Michigan.

Mini-lectures, panel discussions, and roundtable sessions were designed as opportunities for participants to present and discuss ideas, research topics, and challenges in oncology social work research.¹⁶ These included the following:

¹⁴ Zebrack B, Kayser K, Padgett L, Sundstrom L, Jobin C, Nelson K, Fineberg, IC. Institutional Capacity to Provide Psychosocial Oncology Support Services: A Report for the Association of Oncology Social Work. *Cancer*. 2016;122(12):1937-1945. doi:10.1002/cncr.30016

¹⁵ Ibid.

¹⁶ The full agenda for the Research Institute is available in the Appendix.

- Keynote Address: “Notes from the Data-Mines: Research, Practice and Life Lessons Learned from Personal Encounters with Cancer”
- Panel session on “The Funding Quest: Opportunities, Challenges, and Successes”
- Expert-led roundtable discussion sessions on identifying research opportunities in social work practice, careers in oncology social work research, qualitative research, survey research using the AOSW listserv, practice-based research networks/academic-practice community partnerships, research in palliative care/end of life, survivorship research, distress screening research in an international context, oncology social work research with minority communities, intervention research in oncology social work, genetics research in oncology social work, and financial aspects of cancer.
- Presentation on “Publishing Oncology Social Work Research: New Directions for the *Journal of Psychosocial Oncology*”

This White Paper provides a summary of major themes emerging from presentations and discussions at the Post-Conference Research Institute in May 2016.

Major Themes Emerging from Research Institute Sessions

Three major themes of the Research Institute sessions addressed aspects of fostering oncology social work research and bridging the gap between research and practice: 1) the use of clinical data-mining, which provides social workers with a practice-based research strategy; 2) the desirability of establishing an oncology social work practice-based research network, which would provide an ongoing structure for collaborative efforts of multiple groups working together on studies; and 3) the need to pursue a mix of funding strategies for large and small research studies.

Clinical data-mining as a practice-based research strategy for oncology social workers¹⁷

“By systematically ‘mining’ their own available data, social work practitioners can contribute significantly to a truly collaborative [evidence-informed practice] knowledge-building for themselves, their organizations, and the field.”¹⁸ — Irwin Epstein, PhD, MSW, Silberman School of Social Work at Hunter College, City University of New York

Clinical data-mining (CDM), a research strategy that exemplifies the intersection between social work research and practice, presents an opportunity for oncology social workers to reflect on and investigate important questions that arise in their work. As explained in the Research Institute’s keynote address by Irwin Epstein, PhD, MSW, of Silberman School of Social Work at Hunter College, City University of New York, and a pioneer in the use of clinical data-mining by social workers, CDM involves practitioners retrieving their own data for analysis and interpretation, often working in consultation with academic researchers.

The data comprise patient information routinely collected in the course of care, including handwritten case notes, medical records (written or electronic), intake forms, treatment plans, patient satisfaction surveys, and other forms of documentation. Clinical data-mining may be qualitative, quantitative, and use information that has already been collected for other purposes; it also may be supplemented with original data of all kinds.

This approach can illuminate how psychosocial interventions affect outcomes, resulting in practice that is informed by the study findings. For example, a study of patients undergoing renal

¹⁷ Summary of information from a keynote talk and related discussions, “Notes from the Data-Mines: Research, Practice, and Life Lessons Learned from Personal Encounters with Cancer.” Presented by Irwin Epstein, PhD, MSW, professor emeritus, Silberman School of Social Work at Hunter College, City University of New York, on May 7, 2016, at the AOSW Post-Conference Research Institute.

¹⁸ Ibid.

dialysis found that patients who had been counseled by a social worker were substantially less likely to present at an emergency department or be hospitalized than patients who had not had such counseling.¹⁹

“The purposes of clinical data-mining are to enhance practice wisdom, to promote ‘evidence-informed’ practice with multiple sources of evidence, to identify best practices, and ultimately, to promote ‘reflectiveness,’” Dr. Epstein noted.

One recent example of data-mining research is a study of adherence of psychosocial distress screening at two tertiary cancer treatment centers that had adopted prescribed protocols for screening and referral for psychosocial follow-up for patients whose NCCN Distress Thermometer score indicated a clinically significant distress level.²⁰ A retrospective review and analysis of medical records over a 12-week period found that adherence to the screening protocol ranged considerably across seven clinics at the two centers, (from about 48% to 73%); rates of referral for patients with clinical significant distress were about 50% at one center and 64% at the second center. The authors noted that implementing distress screening and responding to patient needs requires institutional investments, and that such investments “will require empirical evidence” demonstrating that screening and appropriate response result in both improved patient outcomes, such as better self-management of symptoms, and in institutional benefits, such as fewer missed medical appointments and decreased rates of hospital readmissions and emergency department use.

APAQCC, the groundbreaking AOSW-sponsored quality-assurance/quality-improvement study mentioned above, is another recent example of clinical data-mining on a large scale. This effort, initiated in 2014 to gather data across 60 cancer programs in North America to assess the programs’ capacity to implement distress screening and to deliver comprehensive psychosocial support services,²¹ was described in a session at the AOSW annual meeting²² preceding the Research Institute.

¹⁹ Dobrof J, Dolinko A, Lichtiger E, Uribarri J, Epstein I. Dialysis patient characteristics and outcomes: the complexity of social work practice with the end stage renal disease population. *Soc Work Health Care*. 2001;33(3-4):105-128. doi:10.1300/J010v33n03_08

²⁰ Zebrack B, Kayser K, Sundstrom L, Savas SA, Henrickson C, Acquati C, Tamas, RL. Psychosocial distress screening implementation in cancer care: an analysis of adherence, responsiveness, and acceptability. *J Clin Oncol*. 2015;33(10):1165-1170. doi:10.1200/JCO.2014.57.4020

²¹ Zebrack B, Kayser K, Padgett L, Sundstrom L, Jobin C, Nelson K, Fineberg IC. Institutional Capacity to Provide Psychosocial Oncology Support Services: A Report for the Association of Oncology Social Work. *Cancer*. 2016;122(12):1937-1945. doi:10.1002/cncr.30016

²² Abstract LI402. Enhancing Institutional Capacity to Deliver Psychosocial Care: A Report from AOSW’s Project to Assure Quality Cancer Care (APAQCC). Presented by Brad Zebrack, PhD, MSW, MPH; Karen Kayser, MSW, PhD; Krista Nelson, MSW, LCSW, OSW-C; Laura Sundstrom, MSW, on May 5, 2016, at the AOSW 32nd Annual Conference, Tampa, Fla.

During one phase of the study, practitioners participating in APAQCC reviewed electronic health records (EHRs) of nearly 9,600 patients during a two-month window. They were looking for documentation indicating whether each patient had been screened for distress and, if so, whether an appropriate clinical response had occurred. APAQCC participants also reviewed the EHRs to determine whether patients had missed appointments, made emergency department visits, or been hospitalized within two months of the screening visit. The investigators found that after accounting for various factors, such as cancer program type and patient age and race, patients who had been screened and received the appropriate clinical response were less likely to have missed an appointment, visited the emergency department, or been hospitalized compared with those who had not been screened or had not received the appropriate clinical response.

Although randomized controlled trials (RCTs) are widely regarded as the gold standard of medical research studies, CDM avoids some requirements of RCTs that may conflict with the values of social workers, such as randomization of interventions and service denial. Data-mining also has its own advantages, notably its utility for exploring a rich trove of unmined “best available” clinical data to answer practice-related questions that are important to practitioners and patients, but that would not be considered priorities for exploring in randomized trials. The expectation that patient data will be widely available in electronic form in the future means that data could be more easily analyzed and amenable to de-identification. The approach is also nonintrusive and relatively inexpensive.

However, CDM studies also have disadvantages, noted Dr. Epstein, including problems such as missing data and validity and reliability issues. In some cases, there are political disputes over ownership of the data. Although CDM studies are relatively low cost, it may be difficult to get funding support. In addition, he said, some journals have a bias against publishing data-mining studies.

Social work researchers should think about how to “demystify” research for clinicians, to help clinicians see research as something that is “part of our commitment to our profession, as part of our opportunities for leadership, as part of our ethics, as really having the expert voice.” said Susan Scarvalone, MSW, LCSW-C, a practitioner-researcher who participated in studies of breast cancer patients at Mercy Medical Center in Baltimore.²³ What helps engage practitioners in research is the realization that it can demonstrate whether an intervention really makes a difference to patients. “We could see that a very simple intervention for addressing fatigue of breast cancer patients helped the women improve,” she said.²⁴

²³ Susan Scarvalone, MSW, LCSW-C, pediatric hospice support specialist for Gilchrist Services in Baltimore, Md. Discussant for “Notes from the Data-Mines: Research, Practice, and Life Lessons Learned from Personal Encounters with Cancer,” on May 7, 2016, at the AOSW Post-Conference Research Institute.

²⁴ Appling SE, Scarvalone S, MacDonald R, McBeth M, Helzlsouer KJ. Fatigue in breast cancer survivors: The impact of a mind-body medicine intervention. *Oncol Nurs Forum*. 2012;39(3):278-286. doi:10.1188/12.ONF.278-286

Practice-based research networks as a bridge between academic researchers and practitioners

“There’s a need for an ongoing practice-based research network in oncology social work, where as a field we could be generating new research questions and use the network to carry out studies on questions of real importance to the field.”²⁵ — Julianne S. Oktay, PhD, MSW, Research Institute chair

Another major theme emerging from the AOSW Post-Conference Research Institute is the use of practice-based research networks (PBRNs) in oncology social work research. PBRNs, which have been operating in medicine and nursing for decades, could provide a way to facilitate research by oncology social workers, explained Sarah Gehlert, PhD, MSW, MA, E. Desmond Lee Professor of Racial and Ethnic Diversity at the George Warren Brown School of Social Work at Washington University in St. Louis, Mo.²⁶

These networks are composed of coordinated groups of practitioners who collaborate with academic researchers to study interventions across settings. In the United States and Canada, the concept of PBRNs began to take shape at the 1979 meeting of the North American Primary Care Research Group, when formation of a national sentinel practice research network was proposed.²⁷ After those spearheading the effort developed the concept, obtained funding, and piloted the new network’s first studies (descriptive studies on headache, pelvic inflammatory disease, and miscarriage), 38 US and Canadian practices began data collection in 1982. These studies led to changes in how physicians approach these problems. By 1994, there were 28 active PBRNs in the North America; by May 2015, there were at least 173.²⁸

According to the Agency for Healthcare Research and Quality (AHRQ), a key source of funding for this type of research, PBRNs typically “draw on the experience and insight of practicing clinicians to identify and frame research questions whose answers can improve the practice of primary care. By linking these questions with rigorous research methods, PBRNs produce research findings that are immediately relevant to the primary care clinician and more easily translated into everyday practice.”²⁹

²⁵ Remarks during AOSW Research Committee Meeting, on May 6, 2016, at the AOSW Post-Conference Research Institute.

²⁶ “Connecting the Data Mines.” Presented by Sarah E. Gehlert, PhD, MSW, MA, E. Desmond Lee Professor of Racial & Ethnic Diversity, Washington University in St. Louis, on May 7, 2016, at the AOSW Post-Conference Research Institute.

²⁷ Green LA, Hickner J. A short history of primary care practice-based research networks: From concept to essential research laboratories. *J Am Board Fam Med.* 2006;19(1):1-10. doi:10.3122/jabfm.19.1.1

²⁸ Agency for Healthcare Research and Quality. <https://pbrn.ahrq.gov/about/history-pbrns> (Accessed July 16, 2016)

²⁹ Agency for Healthcare Quality Research and Quality. <http://www.ahrq.gov/research/findings/factsheets/primary/pbrn/index.html>. (Accessed July 16, 2016)

PBRNs range in scope from local groups, such as the PBRN of community pediatricians in St. Louis, Mo., that provides access to nearly 150,000 children from diverse socioeconomic groups, to national networks, such as an American Academy of Pediatrics PBRN. Key benefits include the following:³⁰

- Research is conducted in context, in the communities in which health care is delivered, instead of in highly selected patients out of context.
- The network provides an opportunity to collect high-quality data on interventions and populations of interest.
- The operation of the network between projects minimizes the time needed to launch a new study and leverages relationships between practitioners and other stakeholders, making the funding of health-related social work more attractive to federal agencies such as AHRQ, as well as foundations.
- The participation of multiple groups working on the same study fosters larger sample sizes and greater confidence in study findings.
- The combination of practice wisdom and academic expertise provides an opportunity to enrich research.
- The ongoing nature of the network provides a natural channel for communication among participants about topics other than network studies, such as the dissemination of practice-changing practice updates from the research literature, or PURLs.

According to Dr. Gehlert, PBRNs must meet certain criteria to qualify for funding from AHRQ, the entity that usually funds PBRN studies. The network must include at least 15 practices and/or 15 clinicians, have a statement of purpose and mission, and plan to exist as an ongoing entity to tackle new research questions, rather than end after a study has been completed. AHRQ also requires a formal organizational structure that includes a director (who is responsible for financial, administrative, and planning functions), and a support staff (at least one person). Other requirements include a community advisory board or other mechanism that can seek advice and

³⁰ Gehlert S, Walters K, Uehara E, Lawlor E. The case for a national health social work practice-based research network in addressing health equity. *Health Soc Work*, 2015;40(4):253-255. doi:10.1093/hsw/hlv060

feedback from the communities of patients, and ongoing communication through newsletters, listservs, email, conference calls, or face-to-face meetings.

Although oncology social workers have not made a concerted use of PBRNs, APAQCC's success in creating a large-scale cooperative research enterprise—enlisting practitioners across North America to assess cancer programs' capacity to implement distress screening and to deliver comprehensive psychosocial support services—demonstrates the potential power of such networks.³¹ In particular, a psychosocial oncology PBRN that functions as a sustainable community of practitioners, oncology social work researchers, and patient advocates, would provide the means to advance the knowledge base and thereby influence system-level changes that will better address the needs of cancer patients and their families.³²

The APAQCC model demonstrates that a PBRN could serve to draw practitioners into research that partners them with academicians. “Many of the participating members in APAQCC said the project got them involved in research in a way they never anticipated, and now they're all fired up,” said Dr. Zebrack, one of the researchers who spearheaded the effort. “We have an opportunity here.”

Multi-institutional studies can also yield comparative data that can help cancer programs identify areas for improvement. In APAQCC, for example, participating programs received a report of their capacity and a comparison of their scores with those of similar (unidentified) cancer programs. Having such data makes it possible, for example, for social workers and hospital administrators to demonstrate to their institutions that social work staffing levels are inadequate or that patient outcomes are poorer compared with those of other institutions, and that resources are needed for improvement.

The Quest for Research Funding

“Social workers need to articulate the unique perspective that we can bring to the fore and how we can advance our profession to address the suffering of cancer patients and families. But we also have to address the realities: funding. We need

³¹ Zebrack B, Kayser K, Padgett L, Sundstrom L, Jobin C, Nelson K, Fineberg IC. Institutional capacity to provide psychosocial oncology support services: A report for the Association of Oncology Social Work. *Cancer*. 2016;122(12):1937-1945. doi:10.1002/cncr.30016

³² “Enhancing Institutional Capacity to Deliver Psychosocial Care: A Report from AOSW's Project to Assure Quality Cancer Care (APAQCC).” Presented by Brad Zebrack, PhD, MSW, MPH; Karen Kayser, PhD, MSW; Krista Nelson, MSW, LCSW, OSW-C; Laura Sundstrom, MSW, on May 5, 2016, at the AOSW 32nd Annual Conference, Tampa, Fla.

the resources to do what we want to do.”³³ — Brad Zebrack, PhD, MSW, MPH,
Research Institute co-chair

Developing a research culture within oncology social work will, unsurprisingly, depend on researchers’ ability to fund studies that address issues that are important to practitioners. Obtaining funding is challenging, but opportunities exist from a variety of sources, ranging from federal agencies, state departments of health and mental health, foundations, health advocacy organizations, pharmaceutical companies, community groups, and others. Developing and maintaining relationships with other researchers, such as well-established oncology social work colleagues or medical researchers who might be interested in incorporating psychosocial component into a study, are also key to building a research career.

The American Cancer Society (ACS), which describes itself as the largest not-for-profit funding source for cancer research, has program grants that support the clinical and/or research training of graduate and doctoral students³⁴ in social work, as well as postdoctoral fellows, said Virginia (Ginger) Krawiec, MPA, the ACS’s director of health professional training grants. The ACS also offers grants to oncology social work researchers at any stage of their career to support studies centered on the psychosocial and behavior aspects of cancer.³⁵

The ACS grant for doctoral students in oncology social work offers benefits beyond the financial support, explained Tara Schapmire, PhD, MSW, speaking of her own experience as an ACS grantee. The networking and mentorship opportunities that arose through the program have continuing benefits for social workers seeking to build a career in oncology social work research.

Investigators should think broadly about possible funding sources for oncology social work research, urged Victoria Kennedy, LCSW, vice president of program development and delivery for the global nonprofit organization Cancer Support Community. She noted that the Cancer Support Community’s Research & Training Institute,³⁶ which conducts cancer-related

³³ “The Funding Quest: Opportunities, Challenges, and Successes.” Panel session at the AOSW Post-Conference Research Institute on May 7, 2016. Moderator: Dr. Brad Zebrack, PhD University of Michigan School of Social Work. Panelists: Ginger Krawiec, American Cancer Society; Victoria Kennedy, Cancer Support Community; Tara Schapmire, University of Louisville School of Medicine; Krista Nelsen, Program Manager for Quality and Research of Cancer Support Services, Providence Cancer Center.

³⁴ Doctoral Training Grants in Oncology Social Work. American Cancer Society. <http://www.cancer.org/research/applyforaresearchgrant/granttypes/doctoral-training-grant-oncology-social-work>. (Accessed on July 16, 2016)

³⁵ American Cancer Society Funding Opportunities for Social Work Training, Research, and Career Development. <http://www.socialworkers.org/pressroom/events/acs.asp>. (Accessed on July 16, 2016)

³⁶ Cancer Support Community, Research & Training Institute. <http://www.cancersupportcommunity.org/our-research>. (Accessed on July 16, 2016)

psychosocial, behavioral, and survivorship research and training, obtains funding for its projects from a range of sources, including pharmaceutical companies, foundations, and partnerships with community organizations or academic partners. Pharmaceutical companies and foundations often put out request for proposals, and social workers might be able to get assistance in tracking those opportunities by consulting with development offices at their institutions, she said. Oncology social workers also may be able to tap into intramural funding at their own institutions, including pilot and innovation awards.

Funding for research projects can arise from less obvious sources, as a result of building relationships with local groups and individuals. Communicating the experience of patients through the “voice” of social work and the patients themselves can be a powerful motivator for philanthropy, explained Krista Nelson, MSW, LCSW, OSW-C, program manager of Compassionate Care and program manager of Quality and Research for Providence Cancer Support Services, in Portland, Ore. Sharing stories with potential donors about the work with cancer patients and their families has opened doors to funding for programs that serve patients in the community and beyond. “For people who are in academia, connect with the clinicians who have the stories if you don’t have them yourself,” she urged.

Panel members and participants also offered additional suggestions about pursuing research funding:

- Forge relationships with a medical institution’s foundation, development office, or media relations departments; these relationships can open doors to raising funds and supporting the institution’s efforts, including research.
- Don’t overlook “grateful donors,” such as patients or family members who want to give back, including through support of research projects.
- Be persistent: Try every avenue of funding.
- Contact a funding agency’s project officer “early and often” for advice and to avoid common errors in grant applications.
- Be aware of “end of the year” research funding opportunities from pharmaceutical company divisions with unspent funds they are eager to allocate quickly to avoid triggering a budget reduction for the following year. Have some ideas ready, ideally two versions (comprehensive and small-scale) of each, to prepare and submit on short notice.

- Keep in mind that with the new emphasis in health care on the “patient experience” and value-based care, social workers are in a unique position to bring the patient voice into their framing of a research proposal.

Disseminating Oncology Social Work Research

To impact the field of psychosocial oncology, oncology social work researchers need to publish their research and to disseminate it to practitioners, as well as to administrators and policy makers. The editor-in-chief of the AOSW-affiliated journal, *Journal of Psychosocial Oncology*, Karen Kayser, PhD, MSW, Professor/LaRocca Chair of Oncology Social Work at the University of Louisville, provided an overview of publishing opportunities and resources for authors. (See “Publishing Oncology Social Work Research,” in the Appendix.)

Next Steps

Work is still needed to better integrate psychosocial services into routine cancer care, overcome racial disparities in the provision of that care, and monitor the quality of care on a system-wide level. Initiatives that educate all providers on patient communication and the provision of psychosocial care are needed, as are efforts to evaluate the extent to which these quality improvement activities truly result in improved patient outcomes and significant cost-offsets. Therefore, our next steps are to develop a sustainable community of cancer patients, oncology social workers, and social work researchers devoted to assuring the delivery of high quality cancer care for all patients and their families. To these ends, and with funding from the Patient-Centered Outcomes Research Institute (PCORI), we will be establishing a Patient-Centered Research Cooperative Group (PCRCG) for Psychosocial Oncology.

A PCRCG for psychosocial oncology will

- 1) Foster collaboration among experienced investigators and skilled psychosocial care providers. Its ultimate purpose will be to define and conduct high-impact, clinically relevant research, and serve as a venue for on-going recruitment of new stakeholders and expertise into the field of psychosocial oncology research.
- 2) Enhance oncology social workers' collective knowledge and ability to design and conduct research, disseminate findings, and achieve systems changes.
- 3) Identify high priority issues and topics of relevance to oncology social workers, and then prepare them for participation in research and the PCRCG.

As oncology social workers, we view research as a process of generating knowledge but also as a form of community-building. It starts with people and intends to strengthen a community as critical for solving a problem. It involves joining together to accomplish more together than anyone could if acting alone, and emphasizes planning and organizing as a means for community members to accomplish their goals.³⁷ When conceptualized as community-building, research can contribute not only to a knowledge base but also to the enhancement of individual competencies and connectedness within an affected community, an enhanced organizational capacity to conduct research, and leadership development.³⁸

As the primary providers of psychosocial care for cancer patients, oncology social workers are trained and well-positioned to influence cancer care delivery at a systems level by participating on their institution's cancer committee (where clinical care policies are deliberated) or by contributing to the generation, dissemination, and implementation of evidence to inform patient-centered care. A PCRCG, coordinated in collaboration with the Association of Oncology Social Work, will significantly increase opportunities for influencing that care.

³⁷ Checkoway B. Core concepts of community change. *Journal of Community Practice*. 1997;4(1):11-29.

³⁸ Checkoway B. Research as Community-Building: Perspectives on the scholarship of engagement. *Gateways: International Journal of Community Research and Engagement*. 2015;8(1):1-11

Acknowledgements

We could not have held the AOSW post-conference Research Institute without the help of many people who worked together to make it happen. We would first like to thank the AOSW Research Committee members (Karen Kayser, Sophia Smith, Elizabeth Rohan, and Hee Yun Lee) who worked on the institute from the formation of the idea to the details of the execution. We also thank all the speakers (especially Dr. Irwin Epstein), the discussants, the panel presenters, and the roundtable leaders, for their thoughtful contributions.

The Research Institute was dependent on the approval of the AOSW Board of Directors, under then-president Penny Damaskos. The AOSW staff, directed by Vicki Loise, handled the registration and all the on-site arrangements: rooms, food, and AV. Thanks especially to Christine Meehan for her on-site help.

We want also to recognize the enthusiasm of the participants, who contributed their ideas and experiences to this first AOSW Research Institute. In addition, the experience was greatly enhanced by the American Cancer Society, which coordinated its annual institute for the doctoral students and mentors in the society's Doctoral Training Grants in Oncology Social Work with this Research Institute, so that the next generation of researchers in this field could participate.

Finally, without the support of Genentech and Medivation, the Research Institute would not have been possible. We greatly appreciate this support and their help in getting a new initiative in oncology social work research off the ground.

Appendix

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The AOSW Post-Conference Research Institute Program Agenda

Friday, May 6 – Saturday, May 7, 2016 ~ Tampa, Fla.

Friday, May 6, 2016

4:00 – 4:30 p.m. Registration

4:30 – 5:45 p.m. Reception and Introductions. Julianne S. Oktay, PhD, MSW, and Brad Zebrack, PhD, MSW, MPH, Research Institute Co-chairs

6:00 – 7:00 p.m. Research Committee Meeting. Julianne S. Oktay, PhD, MSW, Research Committee Director

7:30 p.m. Networking dinner

Saturday, May 7, 2016

8:30 – 9:00 a.m. Registration (Light Breakfast)

9:00 – 10:30 a.m. Welcome and Keynote Address

Welcome to the Research Institute. Alison Mayer Sachs, MSW, CSW, OSW-C; AOSW president; director, Cancer Support Services, Eisenhower Lucy Curci Cancer Center, Rancho Mirage, Calif.

Introduction of Keynote Speaker. Carolyn Messner, DSW, MSW, OSW-C, LCSW-R; director of education and training, CancerCare, New York.

Keynote Address: Notes from the Data-Mines: Research, Practice and Life Lessons Learned from Personal Encounters with Cancer. Irwin Epstein, PhD, MSW; professor emeritus, Silberman School of Social Work at Hunter College, City University of New York, New York.

Discussants:

- Sarah Gehlert, PhD, MSW, MA; E. Desmond Lee Professor of Racial and Ethnic Diversity at the George Warren Brown School of Social Work and the Department of Surgery at the School of Medicine, Washington University in St. Louis, Mo.
- Susan Scarvalone, MSW, LCSW-C; Prevention and Research Center, Mercy Medical Center, Baltimore.

10:30 – 10:45 a.m. Break

10:45 – 11:45 a.m. The Funding Quest: Opportunities, Challenges, and Successes (panel)
Moderator: Brad Zebrack, PhD, MSW, MPH; University of Michigan School of Social Work,
Ann Arbor, Mich.

Panelists:

- Krista Nelsen, MSW, LCSW, OSW-C; manager of Compassion and manager of Quality and Research programs for Providence Cancer Support Services, Portland, Ore.
- Tara Schapmire, PhD, MSW; assistant professor, University of Louisville School of Medicine, Louisville, Ky.
- Victoria Kennedy, MSW, LCSW; vice president of Program Development & Delivery, Cancer Support Community, Washington, DC.
- Virginia (Ginger) Krawiec, MPA; director of the Health Professional Training in Cancer Control program for the Extramural Grants department of the American Cancer Society, Atlanta.

11:45 – 12:00 noon. Break

12:00 – 1:30 p.m. Lunch/Roundtable Sessions

12:00 – 12:45. Roundtable Session 1

1. Identifying Research Opportunities in Your Practice (led by Irwin Epstein)
2. Careers in Oncology Social Work Research (led by Barbara Jones, Elizabeth Rohan)
3. Qualitative Research (led by Julianne S. Oktay)
4. Survey Research Using the AOSW Listserv (led by Karlynn BrintzenhofeSocz);
5. Practice-Based Research Networks/Academic-Practice Community Partnerships (led by Brad Zebrack, Bryan Miller)
6. Research in Palliative Care/End of life (led by Tara Schapmire)

12:45 – 1:30 p.m. Roundtable Session 2

1. Survivorship Research (led by Sophia Smith, Susan Scarvalone)
2. Distress Screening Research in an International Context (led by Carole Mayer)
3. Oncology Social Work Research with Minority Communities (led by Hee Lee)
4. Intervention Research in Oncology Social Work (led by Karen Kayser)
5. Genetics Research in Oncology Social Work (led by Alison Werner-Lin)
6. Financial Aspects of Cancer (led by Christine Callahan)

1:30 – 1:45 p.m. Break

1:45 – 2:15 p.m. Publishing Oncology Social Work Research: New Directions at the *Journal of Psychosocial Oncology*. Karen Kayser, PhD, MSW; professor/LaRocca Chair of Oncology Social Work, University of Louisville; editor-in-chief, *Journal of Psychosocial Oncology*

2:15 – 2:30 p.m. Research Institute Conclusion. Julianne S. Oktay, PhD, MSW, and Brad Zebrack, PhD, MSW, MPH

Biographies

Co-chairs, Speakers, Panel Members, Roundtable Moderators

Karlynn BrintzenhofeSzoc, PhD, MSW, is an Associate Professor at the University of Cincinnati in the School of Social Work. She is also affiliated with the university's Precision Cancer Initiative. Her research interests include screening for distress, instrument development, and the continued use of substances during treatment for cancer.

Christine Callahan, PhD, MSW, is a Research Assistant Professor with the Financial Social Work Initiative (FSWI) at the University of Maryland School of Social Work, where she conducts research to grow the FSWI as a national leader in financial capability. She maintains a strong interest in and dedication to financial stability in vulnerable populations.

Irwin Epstein, PhD, MSW, is Professor Emeritus at the Silberman School of Social Work at Hunter College, City University of New York. Capping an international career devoted to promoting practice-based research conducted by practitioners, Dr. Epstein chaired the 3rd International Conference on Practice Research in 2014. He is also the author of *Clinical Data-Mining: Integrating Practice and Research*, which is currently being translated into Chinese.

Sarah Gehlert, PhD, MSW, MA, is the E. Desmond Lee Professor of Racial and Ethnic Diversity at the George Warren Brown School of Social Work at Washington University in St. Louis and professor in the Department of Surgery. She co-chairs the Prevention and Control Program at the Siteman Cancer Center.

Barbara Jones, PhD, MSW, is Associate Dean for Health Affairs and Professor at University of Texas at Austin School of Social Work, where she is Co-director of the Institute for Collaborative Health Research and Practice. She conducts research on pediatric palliative care, adolescent and young adult cancer survivors, and interprofessional education and practice.

Karen Kayser, PhD, MSW, is Professor/Dr. Renato LaRocca Chair of Oncology Social Work, and coordinator of the psychosocial oncology specialization at the University of Louisville–Kent School of Social Work. She is also Editor-in-chief of the *Journal of Psychosocial Oncology*.

Vicki Kennedy, LCSW, is Vice President, Program Development & Delivery, for the Cancer Support Community (CSC) in Washington, DC, and responsible for development and quality assurance of CSC programs. She is actively working in the areas of distress screening, treatment decision support, and measuring the impact of psychosocial services on the cost of care.

Virginia (Ginger) Krawiec, MPA, is Director of the Health Professional Training in Cancer Control program for the American Cancer Society Extramural Grants department and is responsible for seven grant programs that support the clinical and/or research training of health professionals (nurses, physicians, and social workers). She also directs the Institutional Research Grant program.

Hee Yun Lee, PhD, MSW, MSG, MA, is a Professor and Director of Research at the School of Social Work, University of Minnesota, Twin Cities. Her research focuses on achieving cancer health equity among underserved populations. One of her study areas involves using mobile health technology and developing personalized mobile applications that promote cancer prevention and survivorship.

Carole Mayer, PhD, RSW, is Director of Research and Regional Psychosocial Oncology Lead for the Supportive Care Program at the Northeast Cancer Centre in Sudbury, Ontario, Canada, and Vice President of the Canadian Association of Psychosocial Oncology. Her research has focused on implementing screening for distress programs at the tertiary cancer center and within rural and remote communities.

Carolyn Messner, DSW, OSW-C, FAPOS, LCSW-R, is Director of Education and Training, CancerCare, and is an Adjunct Lecturer at the Silberman School of Social Work at Hunter College. Dr. Messner is Co-editor of the *Handbook of Oncology Social Work: Psychosocial Care for People with Cancer* (Oxford University Press, 2015).

Bryan Miller, MSW, LCSW, OSW-C, is the Lead Oncology Social Worker at Atlanta Cancer Care, which is affiliated with Northside Hospital Cancer Institute, and Assistant Director of the Atlanta Cancer Care Foundation. He is a moderator for AOSW's Social Work Oncology Network listerv and the AOSW state representative for Georgia.

Krista Nelson, MSW, LCSW, OSW-C, is an Oncology Social Worker and Program Manager for Quality and Research of Cancer Support Services, and Program Manager of Compassion at Providence Health & Services. She is a Past President of the Association of Oncology Social Work and on the board of the National Accreditation Program for Breast Centers and other organizations.

Julianne S. Oktay, PhD, MSW, is Professor Emeritus at the University of Maryland School of Social Work and Research Director of AOSW. She has conducted qualitative research on the impact of breast cancer on women (*Breast Cancer in the Life Course*, 1991) and their daughters (*Breast Cancer: Daughters Tell Their Stories*, 2005) and published a "pocket guide" to grounded theory (*Grounded Theory*, 2012).

Elizabeth Rohan, PhD, MSW, LCSW, is a Health Scientist in the Division of Cancer Prevention and Control at the Centers for Disease Control and Prevention, where she conducts behavioral research in patient navigation and cancer survivorship, bringing her 19 years of clinical oncology social work practice to her research endeavors.

Alison Mayer Sachs, MSW, CSW, OSW-C, is Director, Community Outreach & Cancer Support Services, at the Eisenhower Lucy Curci Cancer Center in Rancho Mirage, Calif. She is also President of the Association of Oncology Social Work (2015–2016) and a national speaker on topics such as developing and implementing cancer support services.

Susan Scarvalone, MSW, LCSW-C, is a Pediatric Hospice Support Specialist for Gilchrist Services in Baltimore, Md. Prior to this, she was a Clinical Research Therapist with the Prevention and Research Center at Mercy Medical Center in Baltimore, where she participated in many clinical research studies related to quality of life for cancer survivors.

Tara Schapmire, PhD, MSW, CSW, OSW-C, FNAP, serves on the faculty of the University of Louisville's School of Medicine and the Kent School of Social Work. Dr. Schapmire's research interests include psychosocial care of cancer survivors and their families, gerontology, palliative care, survivorship and interprofessional education.

Sophia K. Smith, PhD, MSW, is Associate Professor at the School of Nursing at Duke University and a member of the Duke Cancer Institute. Dr. Smith's research is focused on mental health and psychosocial care solutions to improve health outcomes for cancer survivors. Her work has helped to define the longitudinal quality of life and patient experience of survivors of adult lymphoma.

Allison Werner-Lin, PhD, EdM, LCSW, is Assistant Professor at the School of Social Policy and Practice at the University of Pennsylvania and Adjunct Investigator in the Division of Cancer Epidemiology and Genetics at the National Cancer Institute. Her research investigates the psychosocial challenges of genetic testing for hereditary cancer syndromes.

Brad Zebrack, PhD, MSW, is Professor of Social Work and member, University of Michigan Comprehensive Cancer Center, Division of Cancer Control and Population Sciences. Dr. Zebrack has clinical social work experience in both pediatric and adult oncology. He served as elected chair for AOSW's research committee from 2003–2008 and 2012–2014.

Publishing Oncology Social Work Research

Editorial direction at the *Journal of Psychosocial Oncology*,³⁹ the official journal of the AOSW, will retain the core mission of this multidisciplinary journal—building and disseminating knowledge that informs the highest-quality psychosocial care to cancer patients and their families—while also promoting access to care for disadvantaged and underserved populations and responding to the substantial challenges of the changing healthcare landscape, explained the journal’s editor-in-chief, Karen Kayser, PhD, MSW.⁴⁰

The Journal publishes original research, including empirically based studies of psychosocial interventions and behavioral cancer prevention in oncology; studies concerning the development and validation of assessment methods for use in practice or research (such as distress screening, and how it relates to practice); and original systematic reviews or meta-analyses of practice-research literature. The journal will continue the tradition of special theme issues.

Researchers seeking to publish their work in the *Journal of Psychosocial Oncology* and other journals should read and follow the author instructions and be mindful of the specific requirements of the journal, including maximum length of the article and abstract, formatting, reference style, and other elements. Some journals require that certain checklists be included, depending on the type of research being reported. Using a checklist may be a helpful guide to authors to ensure that they are including the important elements of their research in the manuscript.

Different checklists address different types of studies:

- For reporting randomized controlled trials, a checklist developed by the CONSORT (Consolidated Standards of Reporting Trials) group: <http://www.consort-statement.org/checklists/view/32-consort/66-title>
- For standardized reporting of nonrandomized controlled trials, The Transparent Reporting of Evaluations with Nonrandomized Designs (TREND) statement: www.cdc.gov/trendstatement
- For cross-sectional, case-control, and cohort studies: www.strobe-statement.org

³⁹ <http://www.tandfonline.com/loi/wjpo20#.V4LUtFcdNGw>. (Accessed July 10, 2016)

⁴⁰ “Publishing Oncology Social Work Research: New Directions at the Journal of Psychosocial Oncology.” Presented at the AOSW Post-Conference Research Institute on May 7, 2016, by Karen Kayser, PhD, MSW, professor/LaRocca Chair of Oncology Social Work, University of Louisville, editor-in-chief, *Journal of Psychosocial Oncology*.

- For meta-analyses and systematic reviews, Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA): <http://www.prisma-statement.org/>
- For qualitative research (interviews and focus groups), Consolidated Criteria for Reporting Qualitative Research (COREQ): <http://intqhc.oxfordjournals.org/content/19/6/349.long>

Serving as a manuscript reviewer is also “an important opportunity for people to contribute to the direction of psychosocial oncology and assure that the Journal publishes the most relevant and timely work,” Dr. Kayser noted in her first editorial as editor-in-chief.⁴¹ “Reviewing Manuscripts for Peer-Review Journals: A Primer for Novice and Seasoned Reviewers,” in the *Annals of Behavioral Medicine*, provides helpful guidance, as well as information about the process of reviewing and publishing, she said.⁴²

⁴¹ Kayser K. Setting the agenda for the journal's new direction. *J Psychosoc Oncol*. 2016;34(1-2):1. doi: 10.1080/07347332.2015.1132055

⁴² Lovejoy TI, Revenson TA, France CR. Reviewing manuscripts for peer-review journals: a primer for novice and seasoned reviewers. *Ann Behav Med*. 2011;42(1):1-13. doi: 10.1007/s12160-011-9269-x

Resources

Association for Oncology Social Work

AOSW's Research Committee welcomes any AOSW members seeking to develop their research skills or initiate their own projects. For more information, contact Julianne Oktay, PhD, MSW, at jojktay@ssw.umaryland.edu.

AOSW-associated completed and ongoing initiatives in psychosocial oncology.
<http://www.aosw.org/projects-partnerships/aosw-projects/>

AOSW's *A Social Work Guide to Conducting Research in Psychosocial Oncology*. (2003).
http://www.aosw.org/AOSW/media/Main-Site-Files/Projects%20and%20Partnerships/Documents/sworg_1.pdf

AOSW Navigator, an e-newsletter that features content created for and by AOSW members, includes a research-related article in each issue. <http://www.aosw.org/publications-media/aosw-navigator/>

Clinical Data-Mining

Clinical Data-Mining: Integrating Practice and Research. Irwin Epstein. New York, NY: Oxford University Press. 2010.

Clinical data mining in an allied health organization: A real-world experience. R. Giles R, Epstein I, and Vertigan A (eds). Sydney: Sydney University Press. 2011.

Epstein I. Using available information in practice-based research: Mining for silver while dreaming of gold. *Soc Work Health Care*. 2001;3(3/4):15-32. doi:10.1300/j010v33n03_03

Epstein I. Reconciling evidence-based practice, evidence-informed practice, and practice-based research: The role of clinical data-mining. *Social Work*. 2011;56(3):284-287. doi:10.1093/sw/56.3.284

Epstein I. Building a bridge or digging a pipeline? Clinical data-mining in evidence-informed knowledge building. *Res Social Work Prac*. 2004;25(4):499-506. doi:10.1177/1049731514536475

Practice-Based Research Networks

Agency for Healthcare Research and Quality (AHRQ). Information about how PBRNs have operated in primary care: <https://pbrn.ahrq.gov/>

Gehlert S, Walters K, Uehara E, Lawlor E. The case for a national health social work practice-based research network in addressing health equity. *Health Soc Work*, 2015;40(4):253-255. doi:10.1093/hsw/hlv060

Funding

American Cancer Society doctoral training grants.

<http://www.cancer.org/research/applyforaresearchgrant/granttypes/doctoral-training-grant-oncology-social-work>

AOSW Web page with general information about grants to support training, research, and career development in areas of interest to oncology social workers. <http://www.aosw.org/professional-development/grants/>

Publishing

Journal of Psychosocial Oncology: <http://www.tandfonline.com/loi/wjpo20#.V4LUtFcdNGw>

Kayser K. Setting the agenda for the journal's new direction. *J Psychosoc Oncol*. 2016;34(1-2):1. doi:10.1080/07347332.2015.1132055

Lovejoy TI, Revenson TA, France CR. Reviewing manuscripts for peer-review journals: a primer for novice and seasoned reviewers. *Ann Behav Med*. 2011;42(1):1-13. doi:10.1007/s12160-011-9269-x



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