Making Whole Person Cancer Care Routine
THE INTEGRATIVE ONCOLOGY LEADERSHIP COLLABORATIVE
JUNE 2023
The Integrative Oncology Leadership Collaborative (IOLC) sought to make whole person cancer care routine by creating, testing, and refining a set of tools for delivering whole person cancer care. Fifteen cancer centers and other organizations participated in the collaborative.
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Integrative oncology uses complementary and lifestyle therapies to support conventional cancer care, manage side effects of treatments, and help patients heal. Whole person care starts with “what matters” most to patients in their cancer care and integrates this care with cancer treatment as well as both integrative and supportive oncology in a person-centered way. This is whole person cancer care. Patients are interested in this approach to cancer care and want support from their oncologists in using these therapies.

A Whole Person Approach Empowers Jenny Leyh to Heal

Jenny Leyh was 33 and in the third trimester of her pregnancy when she was diagnosed with breast cancer in May 2016. “After the initial shock wore off, I was determined to fight the cancer with everything I had,” says Leyh.

Along with her conventional cancer treatments, Leyh used acupuncture, exercise, healthy eating, supplements, cannabis, meditation, and yoga to stay strong during treatment and relieve her anxiety and treatment side effects.

An Aggressive Breast Cancer

Leyh had triple negative breast cancer, stage IIB with a grade 3 tumor. Doctors at Johns Hopkins Medicine recommended chemotherapy—which would not pass through the placenta—before surgery to help combat the cancer without harming Leyh’s baby. Her medical oncologist worked closely with her ob-gyn in developing the cancer treatment plan and monitoring Leyh’s daughter until she was safely born in June 2016.

Knocked Down by Chemotherapy

Over a year, Leyh completed 16 rounds of chemotherapy followed by a bilateral mastectomy with breast implants and tissue expanders and radiation therapy. But as each round of chemotherapy shrank Leyh’s tumor, the harsh treatment also wreaked havoc on her body in other ways. She had joint pain, debilitating fatigue, tender fingernails and toenails, and a general flu-like feeling.

“Patients need help dealing with the overwhelming stress of hearing the words ‘you have cancer.’ That’s where integrative oncology comes in. By utilizing a whole person approach, both provider and patient have important roles in the healing process.”

—Jenny Leyh, breast cancer survivor
Integrative Therapies Relieve Pain, Improve Wellbeing, and Boost Energy
When Leyh had difficulty lifting her daughter due to back pain and stiff joints, she knew she had to take action. Instead of just relying on the pain medications her doctor prescribed, which would cause more side effects, she turned to gentle yoga and acupuncture. Both of these eased her pain.

Getting light exercise regularly and eating healthy improved Leyh's overall wellbeing. Along with yoga, Leyh took light walks. She ate a mostly vegetarian diet.

A Hopeful Attitude After Treatment
Doctors told Leyh she was cancer free in April 2017. But like many cancer survivors, she still had late effects from her treatments and was worried about her cancer coming back.

"I was physically beat up and emotionally struggling, and I felt almost as lost as I had when I was first diagnosed," she says. After a few months of feeling unable to shake the anxiety, Leyh went on a low-dose antidepressant, began to see a therapist, used cannabis to quell the ruminating thoughts and anxiety, started meditating, and continued practicing yoga and getting acupuncture.

"The combination of low-impact exercise, meditation, therapy, cannabis, and the antidepressant helped me through some dark times," says Leyh.

A GROWING NEED FOR A WHOLE PERSON APPROACH TO CANCER TREATMENT
Healing from cancer takes more than eliminating the cancer, as Leyh's story shows. A whole person approach supports conventional cancer care by empowering and engaging patients to take an active and preventive role in their health. It combines conventional care (chemotherapy, radiation, and surgery) with complementary and lifestyle therapies such as nutrition, exercise, acupuncture, and yoga, and supports whole person healing.

Cancer patients are increasingly using complementary and lifestyle therapies. They want support from their oncologists and cancer centers in doing this.

Barriers to Delivering Integrative Oncology
With the number of cancer cases on the rise, the need for an integrative approach to oncology is growing. Yet, the barriers to delivering this care are high:

- The conventional focus on eliminating the cancer.
- A shortage of oncologists.
- A lack of awareness and education about integrative oncology.
Conventional cancer care focuses on eliminating the cancer. This approach ignores knowledge about the micro- and macro-environments in which cancer grows and how patients with cancer heal.

**Evidence Supporting Integrative Oncology**

A growing body of evidence shows that adding complementary and lifestyle approaches to conventional cancer treatment benefits patients by helping them manage the side effects of treatment, improving patient-reported outcomes and contributing to improved overall survival.

Institutions that provide six simple whole person care services and integrate them with conventional cancer care showed a significant increase in five-year survival odds:

1. Exercise counseling.
2. Nutrition counseling.
3. Patient support groups.
4. Psycho-oncology support.
5. Spiritual services.
6. Meditation/mindfulness.

**The Oncologist Shortage**

As demand for oncology care increases due to an aging and better-insured population, the American Society of Clinical Oncology (ASCO) is projecting a shortage of more than 2,200 oncologists by 2025.

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**ASCO 2020 Snapshot of the Oncology Workforce**

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<tr>
<th>Age of Oncologists</th>
<th>Rural America</th>
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<tr>
<td><strong>19.7%</strong> of oncologists are nearing retirement age (64+).</td>
<td><strong>1 in 6</strong> Americans live in a rural area.</td>
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<tr>
<td><strong>15.6%</strong> of oncologists are age 40 or under.</td>
<td><strong>32 million</strong> Americans live in a county without an oncologist.</td>
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<td><strong>4 in 10</strong> Americans in rural areas who have or had cancer say that there are no cancer specialists near where they live.</td>
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Lack of Integrative Oncology Awareness and Education

The lack of awareness of and education on the effectiveness of integrative modalities makes it difficult for oncologists to understand the importance of complementary and lifestyle therapies to patients. “My experience with mainstream oncology is that there is often a very conservative approach to how providers view integrative modalities,” says Leyh.

During her cancer treatment, Leyh found and used complementary and lifestyle therapies on her own. She informed her oncologist about this, but her oncologist “had little to say.”

Patients Want Support from their Oncologists

A survey of 164 breast cancer patients and 115 oncologists conducted in 2020 found that patients were significantly more likely to use complementary and lifestyle therapies if their oncologist recommended it. A NEW APPROACH TO INTEGRATIVE ONCOLOGY

An integrated oncology approach called whole person cancer care will help oncologists and other members of oncology care teams effectively and efficiently deliver integrative oncology. Whole person cancer care is focused on what matters most to the patient and integrates each patient’s personal determinants of healing into their cancer care.

Like integrative oncology, whole person cancer care uses complementary and lifestyle therapies to combat the side effects of cancer care and help restore the quality of life for our patients. Through the inclusion of evidence-based therapies such as nutrition, movement, meditation, and others, patients will activate their individual ability to heal as they go through cancer treatment and into survivorship.
The Integrative Oncology Leadership Collaborative

The Integrative Oncology Leadership Collaborative (IOLC) was designed to help oncology care teams make whole person cancer care routine. Participants from 15 cancer centers and other organizations created, tested, and refined a set of tools for delivering whole person cancer care. The tools streamline the delivery of whole person cancer care. Each cancer center team also developed and began implementing a plan to use the tools.

The collaborative was funded from April 2021 to December 2022 with a grant from the Samueli Foundation. Wayne Jonas, MD, and Alyssa McManamon, MD, FACP, led the collaborative. Dr. Jonas, the lead faculty member, is a clinical professor of family medicine at Georgetown University, president of Healing Works Foundation, and author of How Healing Works. Dr. McManamon is a triple-board certified hematologist-oncologist and associate professor of internal medicine and neurology at Wright State University's Boonshoft School of Medicine. Previously director of advanced clerkship programs for the F. Edward Hebert School of Medicine at the Uniformed Services University in Bethesda, MD, she is currently at the Dayton VA Medical Center where she runs a Whole Health Oncology clinic and mentors trainees in the hematology-oncology fellowship program.
Whole person cancer care examines “what matters” versus “what’s the matter” when treating cancer in a patient.

In the Whole Person Cancer Care Framework, the current disease-focused, transaction-based treatment model is integrated with a person-centered, relationship-based, health promotion and recovery model.

The Whole Person Cancer Care Framework is based on the Two-Circle Model of Whole Person Care, a communication and operational model for implementing high-quality health care at a systems level published in a 2022 *Journal of the American Medical Association* article.

Developed for the transformation of care in the Veterans Health Administration, this model is being adopted in primary care, oncology, neurology, pain management, and other care delivery sectors. Its implementation is the focus of a current National Academy of Medicine consensus study.
THE FOCUS OF WHOLE PERSON CANCER CARE

The Whole Person Cancer Care Framework involves:

1. Asking each patient what their purpose in life is.
2. Having a team with health partners or advocates that maintain an ongoing relationship with each patient.
3. Organizing a suite of health promotion and recovery-focused services, such as non-pharmacological, complementary health, and lifestyle support services.
4. Providing access and coverage policies for care using a value-based payment system adjusted to address social needs that facilitate equity.

Delivering high-quality care also necessitates continuous innovation and improvement, so an eye on evaluation and quality improvement is necessary.

TOOLS FOR WHOLE PERSON CANCER CARE

Providers use the HOPE note toolkit for cancer care to deliver whole person cancer care:

- Personal health inventory (PHI).
- Integrative health visit and the HOPE note.
- Personalized health plan.
- Related resources.

The PHI, integrative health visit and HOPE note, and personalized health plan are part of the HOPE note toolkit, designed for use in primary care. The IOLC created, tested, and refined versions of these tools specifically for whole person cancer care.

The Personal Health Inventory

The PHI is a way for oncology care teams to explain whole person cancer care to patients and focus the discussion on determinants of health and healing and self-care. Patients usually fill out the PHI before the integrative health visit.

The Integrative Health Visit and the HOPE Note

The HOPE note is a tool to elicit information to better understand a patient’s issues during an integrative health visit. It builds off the SOAP (subjective, objective, assessment, and plan) note and goes beyond the regular medical visit.
HOPE Note Questions

Body and External:
- What is your home like?
- Your work environment?
- Do you get out in nature?

Social and Emotional:
- How is your social support?
- How was your childhood?
- Can you meet your economic needs?

Behavior and Lifestyle:
- How is your diet?
- How is your sleep?
- How is your stress?
- How is your activity level?

Spiritual and Mental:
- What brings you joy?
- What is the most important thing in your life?

Oncology care teams use the PHI and the HOPE note during an integrative health visit to identify and address what matters most to the patient. This process helps engage the patient in shared decision-making about their health and healing, putting them front and center in the care plan. Providers offer evidence and support to help patients meet their goals.

The Personalized Health Plan

During the first integrative health visit, the provider and patient work together to create a personalized health plan, which is integrated into the cancer treatment plan. The personalized health plan lists up to three things the patient wants to work on first and address what matters most to them. Also, it includes steps for making progress along with resources and support.

Related Resources

Related resources created for whole person cancer care include the Integrative Oncology Solution Guide for providers and pocket guides for patients and providers.

The Integrative Oncology Solution Guide

The Integrative Oncology Solution Guide is a new tool developed to help providers conduct integrative health visits and address areas patients are ready to work on to improve their health. Providers personalize the guide to their cancer center and put it into a usable format for their workflow.
The guide covers five areas: nutrition, sleep, stress management, activity, and economic and social support. The page on each area starts with the relevant HOPE note questions and then lists recommended actions for providers to choose from in four categories:

- Educational handouts for self-care.
- Technology.
- Internal resource or specialist.
- Community resources.

Pocket guides

Pocket guides for patients and providers provide easy-to-read information about topics that are important to people with cancer. Most guides include information about behavioral and lifestyle treatments people can use to feel better. Some offer ways to cope with the physical and emotional side effects of cancer treatment.

Pocket Guides

- Young Adult and Teen Cancer.
- Financial Impact of Cancer.
- Cancer and Sexual Health.
- Cancer and Spirituality.
- Nutrition and Cancer.
- Movement and Cancer.
- Cancer Pain.
- Peripheral Neuropathy.
- Supplements and Cancer.
- Cannabis and Cancer.

Read and download the pocket guides.
Tools for Whole Person Cancer Care

The IOLC helped develop a set of tools for delivering whole person cancer care and learned more about patient needs.

Oncology care teams from nine cancer centers participated in the IOLC in year one:

1. Ann B. Barshinger Cancer Institute, Lancaster General Hospital, Penn Medicine.
2. DeCesaris Cancer Center, Luminis Health Anne Arundel Medical Center.
3. Inova Schar Cancer Institute.
4. James M. Stockman Cancer Institute, Frederick Health.
5. Johns Hopkins.
6. Karuna Precision Wellness Center.
7. Mayo Clinic Jacksonville.
8. Sidney Kimmel Cancer Center, Jefferson Health.
9. Susan Samueli Integrative Health Institute, University of California Irvine.

The other members of the collaborative included Donald Abrams, MD, of the UCSF Osher Center for Integrative Health and others from IQVIA and the National Cancer Institute. All acted as subject matter experts who provided feedback and advice to the collaborative.

YEAR ONE ACTIVITIES

During year one, the oncology care teams:

- Provided feedback on a set of tools and resources for delivering whole person cancer care drafted by the team.
- Began to focus more on including the patient voice in designing whole person cancer care.

Team members attended 10 monthly web-based sessions focused on whole person cancer care tools and topics related to services and delivery processes. They supported and learned from each other and from the collaborative leaders.
KEY RESULTS

Members of the IOLC helped develop a set of tools for delivering whole person cancer care and learned more about patient needs during year one.

Developing Cancer-Focused Tools and Resources

The IOLC developed and translated the HOPE note toolkit for cancer care.

“We created oncology-specific content, including patient-facing pocket guides, and adapted the PHI to the cancer population,” says Dr. McManamon.

**The personal health inventory**

Based on feedback from members of the IOLC, the team revised the PHI by:

- Deleting questions that were not appropriate for cancer patients. The PHI for cancer care does not include questions about the number of healthy days during the past 30 days and “Why do you want to be healthy?”
- Adding the Functional Assessment of Cancer Therapy–General 7 (FACT-G7) to assess “How is your health and wellbeing now?” FACT-G7 is based on seven statements that are most relevant to people with cancer over the last seven days, such as “I have a lack of energy.” Patients rated each item on a scale of zero (not at all) to four (very much).
- Adding “What is most important for you in life? What brings you joy?” in place of “Why do you want to be healthy?”
- Adding a new Patient Dignity Question (PDQ): “What do I need to know about you as a person to give you the best care possible?”

**The integrative health visit/HOPE note and the personalized health plan**

The IOLC did not suggest any changes to the HOPE note or the personalized health plan. Many of the cancer centers are looking at ways to adapt the HOPE note for their settings and implement it into the Electronic Health Record.

**Related resources**

The IOLC reviewed the Integrative Oncology Solution Guide and made suggestions for revisions. For example, the title was shortened from Integrative Oncology Non-Drug and Self-Care Solution Guide to Integrative Oncology Solution Guide based on feedback from members.
Learning More About What Matters to Patients

Patient engagement and understanding are crucial in the adoption of whole person cancer care. As a breast cancer survivor, Leyh offered the patient perspective on topics discussed during year one.

While this was very helpful to the members of the IOLC, they realized that an effort to empower patients was also necessary. Collaborative leaders and Leyh made plans to add sessions on patient advocacy and add more patient voices in year two.

TOPICS COVERED

Key topics covered in the monthly web-based sessions included survivorship, integrative oncology group medical visits, and payment for integrative oncology.

SURVIVORSHIP

Throughout the IOLC, participants discussed survivorship.

Definitions of Survivorship

American Cancer Society
"The American Cancer Society uses the term cancer survivor to refer to anyone who has ever been diagnosed with cancer no matter where they are in the course of their disease."

ASCO
"A person who has had a cancer diagnosis is oftentimes called a ‘cancer survivor.’ When people talk about ‘survivorship,’ they are usually referring to navigating their life experiences and challenges resulting from their cancer diagnosis."

National Cancer Institute
"In cancer, survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond. The survivorship experience also includes issues related to follow-up care (including regular health and wellness checkups), late effects of treatment, cancer recurrence, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience."

“Empowering patients to self-advocate is key in the uptake of integrative modalities that will support healing and restore quality of life during cancer treatment and beyond.”
—Jenny Leyh
These definitions are aligned with the National Coalition for Cancer Survivorship's shift from the definition of survivor being post-treatment to the moment of diagnosis and beyond.

Today, experts estimate that 17 million people living in the United States are cancer survivors, and about two out of every three people diagnosed with cancer will be alive at least five years after diagnosis. The increase in the number of cancer survivors has made planning for life after cancer an essential part of cancer care.

The Missing Roadmap for Cancer Survivors

While Leyh was declared “cancer free,” she experienced significant collateral damage after completing her treatment.

“During active treatment, I was in ‘fight mode.' I had a treatment schedule to keep up with and thankfully it was working,” she says. “But when I rang the bell signifying the end of treatment, I was also opening a new door to life beyond cancer, and the feelings that arose were complex.”

Like many cancer survivors, Leyh felt lost without the constant medical monitoring.

“They don't give you a roadmap for life after a cancer diagnosis,” she says. “That aspect of cancer care needs to be improved so that survivors feel better supported after they complete treatment.”

The Need for a New Approach to Survivorship

While many cancer centers currently provide some survivorship services, cancer survivors need more help than they usually receive. Often, services are based on guidelines such as those of the Commission on Cancer or the National Comprehensive Cancer Network NCCN Guidelines® Insights: Survivorship, Version 1.2022. The Commission on Cancer guidelines, for example, call for counseling and a survivorship summary.

By focusing on what matters most to patients, the HOPE for Cancer Care tools will help oncology care teams improve survivorship services. But more work is needed to adequately address the individual needs of cancer survivors.

“The survivorship summary is a very comprehensive, accurate document but it provides information in a way that wasn’t necessarily accessible and was certainly not customized for patients.”

— Randall A. Oyer, MD, FACCC, executive medical director, Ann B. Barshinger Cancer Institute; clinical professor of medicine, Perelman School of Medicine, University of Pennsylvania
INTEGRATIVE ONCOLOGY GROUP MEDICAL VISITS

Group medical visits, also known as shared medical appointments, combine medical care, health education, and peer interaction. Leading integrative oncologist Donald Abrams, MD, started integrative oncology group medical visits at the UCSF Helen Diller Family Comprehensive Cancer Center in late 2018. Dr. Abrams is also a professor emeritus of medicine at the University of California San Francisco.

The two-hour integrative oncology group medical visits include:

• Didactic content presented by the physician.
• Time for patient questions.
• Individual consultations in a nearby room, which allows group visits to be billed.

Each group has six to 12 patients. The three sessions cover cancer nutrition, plant therapies, and nontraditional medicine. They were held two weeks apart.

Participants received generic advice during the didactic portion of the group and individualized advice based on diagnosis during one-on-one consultations. They also received handouts on the content.

Benefits of Group Medical Visits

Results of a study of five groups with 32 patients showed that:

• Patients were very satisfied with the program. They rated all aspects of the program as >4.0 on a five-point Likert scale.
• Group visits are a financially viable alternative to individual integrative oncology visits. Revenue from group visits exceeded the revenue potential of six hours of individual visits by an average of 38%.13

Dr. Abrams and his team concluded that group medical visits “are a feasible and promising model for increasing access” to integrative oncology.

See Payment for Integrative Oncology for more information coding and billing for integrative oncology visits.

Increasing Access to Integrative Oncology with Group Medical Visits

Dr. Abrams started group medical visits as a way to increase patient access to integrative oncology at the UCSF Helen Diller Family Comprehensive Cancer Center. “People were waiting three to six months to see me for an integrative oncology visit,” he says. “For people with cancer, that’s a long time to wait.”

Initially, the group medical visits in integrative oncology were held in person at the cancer center. During the COVID-19 pandemic, patients participated by Zoom. They interacted with each other more by Zoom, says Dr. Abrams. Going forward, it remains to be determined whether group medical visits will be held in person, virtually, or both.

“I love doing the group visits and the patients love being part of the group visits,” says Dr. Abrams.
PAYMENT FOR INTEGRATIVE ONCOLOGY

While patients are interested in integrative oncology, the out-of-pocket cost is a barrier for many of them. A survey of 164 breast cancer patients conducted by IQVIA showed that:

- The costs of complementary and lifestyle therapies were only fully covered by patients' health systems 4% to 26% of the time.
- Patient support groups and nutrition consultation were the only therapies that were fully funded at least 20% of the time.
- $25 is a reasonable amount for patients to pay for integrative oncology services.8

By generating revenue from integrative oncology services, providers can make it financially feasible for patients to use these services. Proper coding can enable providers to bill for individual and group medical visits.

Evaluation and Management Coding Based on Time

Providers should use evaluation and management codes for medical decision-making based on complexity and time. Documentation must cover the level of complexity in the problems addressed but no longer needs to describe the complexity of each item addressed during the visit.

Since 2021, the Current Procedural Terminology has allowed providers to code for time spent on the day of a patient visit preparing for the visit and for follow-up work. This covers activities such as reviewing records, writing notes, and making calls, for example, to an acupuncturist. Providers can code in 15-minute increments and for prolonged services.

Coding for Group Medical Visits

Dr. Abrams has been able to generate more revenue from group medical visits by coding by complexity, not time. Even though some patients were unable to attend all three visits and payers varied, the revenue from group visits "significantly exceeded the revenue potential compared with the same amount of time spent in individual visits."13

It was 84% more efficient for a provider to see more patients in a group medical visit than to do private, one-hour visits.13

Dr. Abrams documented patient visits in the electronic health record using a short note template. With the template and dot phrases, he was able to adequately document each patient visit for coding and billing purposes in about five minutes. Dot phrases are SmartPhrases in Epic that allow providers to insert common text into patient notes by typing a period followed by a short user-generated phrase.
Whole Person Cancer Care in Practice

Members of the IOLC implemented the HOPE for Cancer Care tools in their cancer centers, expanded the patient’s voice in whole person cancer care, and created more resources for patients.

Thirteen cancer centers participated in the IOLC in year two. Eleven of the oncology care teams came from U.S. community cancer centers and NCI-Designated Cancer Centers, as well as a cancer rehabilitation and wellness center. Two teams represented wellness and/or integrative therapy programs within cancer centers. The IOLC also included one cancer center each from Canada and Israel.

IQVIA and the National Cancer Institute continued to provide feedback and advice to the collaborative.

NEW CANCER CENTERS IN YEAR TWO

1. Davidoff Cancer Center, Rabin Medical Center, Israel.
2. Memorial Sloan Kettering Cancer Center.
3. Carrillo Kern Center for Integrative Therapies, Sentara Integrative Therapy Center, Sentara Health.
4. ACTION (Alberta Complementary Therapy and Integrative Oncology) Centre, University of Calgary, Canada.

CONTINUING CANCER CENTERS

5. Ann B. Barshinger Cancer Institute, Lancaster General Hospital, Penn Medicine.
6. De Cesaris Cancer Center, Luminis Anne Arundel Medical Center.
7. Inova Schar Cancer Institute.
8. James M. Stockman Cancer Institute, Frederick Health.
10. Karuna Precision Wellness Center.
11. Mayo Clinic Jacksonville.
12. Sidney Kimmel Cancer Center, Jefferson Health.
13. Susan Samueli Integrative Health Institute, University of California Irvine.

YEAR TWO ACTIVITIES

During year two, the oncology care teams developed and implemented a plan to advance whole person cancer care at their centers using the HOPE for Cancer Care tools. They continued to provide feedback to refine the tools.

In planning and managing implementation and to evaluate their changes and plan next steps to advance whole person cancer care, the teams used the Plan-Do-Study-Act (PDSA) cycle. The PDSA cycle is a tool for documenting change.
Most teams presented their plans to the group in the first few months of year two and their achievements and challenges during the last few months. They made the presentations during 10 monthly web-based meetings and eight optional office hours. Participants from other teams provided feedback on the plans, achievements, and challenges. Also, participants continued to support and learn from each other.

KEY RESULTS

Members of the IOLC:

• Planned, piloted, and implemented the HOPE for Cancer Care tools in their cancer centers and shared their work with the group.
• Expanded the patient’s voice by working with more patient advocates, learning more about the patient’s perspective, and creating more resources for patients.

Moving the Tools into the Clinical Space at Cancer Centers

The participating cancer centers used a variety of approaches to whole person cancer care, including focusing on one area of cancer care, models within and outside of a health system, a small team in a community cancer center, and centers focused on integrative oncology or integrative health.

Examples of work in whole person cancer care

Here are of some of the work being done by the participating cancer centers.

Ann B. Barshinger Cancer Institute, Lancaster General Hospital, Penn Medicine

The Ann B. Barshinger Cancer Institute, a community cancer center (Lancaster, Pennsylvania), focused on one area of cancer care: survivorship. Established in 2013 as part of Penn Medicine Lancaster General Health, the cancer institute supports the mind, body, and spirit of patients and their families. It is affiliated with Penn Medicine’s Abramson Cancer Center, an NCI Comprehensive Cancer Center.

During the IOLC, the Ann B. Barshinger Cancer Institute developed a new integrative approach that moved beyond survivorship to survivorship and wellness. Dr. Oyer and his team:

• Identified the problems to be solved.
• Developed a process for moving toward wellness.
• Began implementing parts of the process.

An advanced practice nurse is the primary contact for patients and their families. Information technology professionals have created a smart form in Epic that embeds the HOPE note.

“When wellness reframed what we need to do to connect with, support, and serve our cancer patients as they recover from the effects of the cancer diagnosis and its treatment.”

—Randall A. Oyer, MD, FACCC
The survivorship and wellness team is:

- Designing a new workflow.
- Developing a list of in-house and community services and resources for wellness and recovery.
- Working with information technology to automatically identify patients who are ready to schedule a wellness–survivorship care visit and automate the process.

**Models within and outside of a health system:**

**Inova Schar Cancer Institute and Karuna Precision Wellness Center**

Inova Schar Cancer Institute is part of Inova, northern Virginia's leading nonprofit health care provider. The integrated network has hospitals (with 1,952 licensed beds), primary and specialty care practices, emergency and urgent care centers, outpatient services, and destination institutes.

Karuna Precision Wellness Center (Indianapolis, Indiana) is a cancer rehabilitation and wellness center that is not affiliated with a health system.

Both models are providing whole person cancer care.

**The Inova Schar Cancer Institute**

Life with Cancer is an integrative cancer program within the Inova Schar Cancer Institute. Its purpose is “to enhance the quality of life of those affected by cancer by providing evidence-based education, support, wellness programs and integrative therapies.” Life with Cancer is embedded in each of Inova’s five hospitals and also has one 16,000-square-foot standalone center. It is funded by philanthropy (50%) and by Inova (50%).

The program offers:

- Supportive counseling and consultations on what to expect from cancer and treatment.
- Classes on healthy living, integrative therapies, stress management, and more.
- Special guest speakers and conferences.
- Community presentations at businesses, universities, health fairs, and more.
- Groups to connect with other patients and families.

All services (except massage and psychiatry) are free for patients, survivors, and their family members.

**Karuna Precision Wellness Center**

Pediatric oncologist Jamie L. Renbarger, MD, MS, started the nonprofit Karuna Precision Wellness Center after being frustrated by the lack of care and resources for people with cancer who had been cured or finished their treatment. Dr. Renbarger is a professor of pediatrics, division chief of pediatric hematology/oncology, the Caroline Symmes professor in pediatric cancer research, and director of the Pediatric Cancer Precision Genomics Program at Riley Hospital for Children.

> “After treatment people feel very isolated and on their own and are not sure how to get back to the full, healthy lives that they want to live.”
> —Jamie Renbarger, MD, MS
Karuna Precision Wellness Center provides evidence-based integrative health services designed to help relieve the negative effects of cancer and reduce the risks of recurrence. After a full complementary assessment, staff develop a personal care plan to address the physical, mental, and nutritional needs of each person. Karuna Precision Wellness Center provides the following services:

Physical health:
- Exercise.
- Massage.
- Acupuncture.

Mental health:
- Counseling.
- Neurocognitive Therapy.

Nutritional health:
- Personalized menu plan or recipe book.
- Follow-up sessions on the plan.
- Supportive diets, supplementation, and applicable testing.

DeCesaris Cancer Center, Luminis Anne Arundle Medical Center
Luminis Health is a nonprofit health system with three hospitals (Annapolis and Lanham, Maryland). Anne Arundle Medical Center has more than 400 beds. Young Lee, MD, joined Anne Arundle Medical Center to build an integrative oncology program. Dr. Lee’s team manages the program with the help of an acupuncturist and a medical assistant.

During the IOLC, Dr. Lee conducted a quality improvement study to assess the experiences of patients who were already using integrative oncology and gauge interest in the center’s integrative oncology program. Of the 101 patients surveyed, about 30% did not use any complementary and alternative medicine therapies. The vast majority used two or three modalities. Acupuncture, which Dr. Lee was adding to the program, was the top therapy patients wanted, followed by other modalities and then massage and diet/nutrition.

Dr. Lee also conducted a PDSA project to evaluate patient satisfaction with four pocket guides. Eight patients read the pocket guides and took a five-question survey. Results shows that:
- All patients found the pocket guides very or somewhat helpful and very easy or easy to read.
- Seven out of eight patients were very or somewhat likely to recommend the pocket guides to others.

The next steps for the integrative oncology program include offering group acupuncture for specific conditions, starting virtual group medical visits, and conducting clinical trials in integrative oncology.

Carrillo Kern Center for Integrative Therapies, Sentara Integrative Therapy Center, Sentara Health
Sentara is an integrated, nonprofit health care delivery system with 12 hospitals in Virginia and northeastern North Carolina. The Sentara Brock Cancer Center is the regional hub of the Sentara Cancer Network.
Opened in April 2022, the Carrillo Kern Center for Integrative Therapies at the Sentara Brock Cancer Center provides acupuncture, mind-body, massage, nutrition, and Reiki. To build a referral base, center staff gave physicians tours and let them try some integrative health services, such as Reiki. Within a few months, the center expanded the number of days services are offered and the population served to include all hospice patients, cancer survivors five or more years post-treatment, and caregivers of cancer patients.

During the IOLC, the oncology care team conducted a PDSA study to evaluate adding the PHI questions into care pathways. They trained oncology nurse navigators to administer the PHI and make recommendations for integrative therapies based on the results and a checklist of internal and external referrals. The oncology care team embedded the PHI and the HOPE note into Epic and developed a report to analyze aggregate responses.

Of the eight patients who participated in the study, three patients received referrals for integrative therapies; however, none accessed the services. Three patients declined services, and results for the other two patients are unknown.

Next steps for the team at Carrillo Kern Center for Integrative Therapies include:

- Stabilizing oncology nurse navigator staffing and educating them on using the PHI and integrative services.
- Establishing a process and time period for reassessing patients using the PHI and reviewing trends across time.
- Taking a proactive approach and scheduling appointments for recommended integrative services.

**Sidney Kimmel Cancer Center, Jefferson Health**

The Sidney Kimmel Cancer Center is part of Jefferson Health, a network of 18 hospitals and physician practices throughout the Philadelphia region. The NCI-Designated Cancer Center is certified by the American Society for Clinical Oncology for providing Patient-Centered Cancer Care.

The Supportive Care & Cancer Survivorship program provides cancer patients, many of whom speak Spanish, with relief from symptoms, pain, and stress. During the IOLC, the oncology support services team launched and evaluated group medical visits and began work to offer more services and resources in Spanish.

The three-part Supportive Medicine Care Visits is co-led by Ana Maria Lopez, MD, MPH, MACP, FRCP, and a social worker. The two-hour group medical visits focus on helping people with cancer and their caregivers identify and develop goals related to quality of life. The PHI and the HOPE note are woven throughout the visits, which cover three topics:

- Cannabis and supplements.
- Energy and activity.
- Relationships and sexual function.

Initial group medical visits were held in English. The team plans to also offer them in Spanish.

The oncology support services team conducted a needs assessment study to evaluate the group medical visits and other supportive care services. Two-thirds of the 184 respondents were interested in joining a virtual support group. Of other supportive care services, respondents were most interested in nutrition, mindfulness/stress reduction, and programs to manage side effects.
Dr. Lopez also wanted to provide patient resources in Spanish. The team worked with her to translate some of the pocket guides into Spanish.

**University of California Irvine, Susan Samuelli Integrative Health Institute**

UCI Health, the clinical enterprise of the University of California Irvine (UC Irvine), is a 459-bed acute care hospital providing tertiary and quaternary care, and ambulatory and specialty medical, behavioral health and rehabilitation services (Orange, California). The Susan Samuelli Integrative Health Institute helps patients achieve optimal health through an interdisciplinary, evidenced-based, integrative approach to health and wellness.

During the IOLC, the Susan Samuelli Integrative Health Institute hired Sandy Colvard, ND, FABNO, a naturopathic oncologist, to work with a breast cancer oncologist and other providers in the UCI Health breast cancer clinic. Dr. Colvard focuses on providing patients with cancer safe options for combining conventional cancer treatment with natural and supportive therapies. She helps patients:

- Support the immune system.
- Reduce or eliminate conditions that promote cancer.
- Improve diet and nutrition.
- Reduce the side effects of chemotherapy and radiation therapy.

Dr. Colvard's initial intake is very similar to the HOPE note. Much of her work involves understanding which supplements patients are already taking and teaching them what they should and should not take. She also focuses on nutrition.

**Expanding the Patient Voice**

After a successful first year of the Integrative Oncology Leadership Collaborative, the team established the Patient Advocacy and Empowerment Collaborative, a group of six cancer survivors who met monthly in tandem with the IOLC. The group presented on the subject of whole person advocacy and empowerment in two sessions with the IOLC and also created more resources for patients.

The Patient Advocacy and Empowerment Collaborative ensured that patient perspectives were central to the work of the IOLC. The patient collaborative:

- Reviewed and provided feedback on the tools created by the IOLC.
- Created new resources for patients.
Making Patient Perspectives Central in Cancer Care

Only cancer survivors understand the unique challenges associated with all phases of cancer treatment during active treatment and beyond. “Patient advocacy ensures that the patient perspective is always considered in a variety of forms. Cancer patients need to feel that their voice and perspective is heard,” says Leyh.

In year two of the IOLC, Leyh established the Patient Advocacy and Empowerment Collaborative to ensure that patient perspectives were central to the collaborative’s work. The Patient Advocacy and Empowerment Collaborative is a focus group made up of Leyh and five other cancer survivors. The group met monthly to review and provide feedback on the tools created by the IOLC and to create new resources for patients.

“Our collective voices and perspectives as cancer survivors will ensure that the focus of our work is always centered around the patient,” says Leyh.

Two sessions on whole person advocacy and empowerment highlighted experiences with and barriers to integrative oncology and provided recommendations for oncology care teams on how to engage patients in whole person cancer care. The content was presented by Leyh and based on experience and insights of the members of the Patient Advocacy and Empowerment Collaborative.

The Patient Advocacy and Empowerment Collaborative’s recommendations to better support patients' use of integrative oncology include:

- Start with the oncologist.
- Assign a social worker or nurse navigator to help patients access and use integrative oncology services.
- Treat patient as partners.
- When presenting nutrition and exercise, frame the conversation in a gentle and encouraging way. For example, “these are some ways in which you can get some control back and make your body inhospitable to cancer cells.”
- Explain that complementary treatments support healing and often reduce recurrence.
- Focus on the individual, who is more than their cancer.

New resources created for patients include a landing page on whole person cancer care, pocket guides, and longer guides. The landing page, with sections on diagnosis, treatment, and survivorship, offers free pocket guides and other resources.
The Patient Advocacy and Empowerment Collaborative reviewed existing pocket guides and helped develop versions focused on cancer. Also, they helped develop new cancer pocket guides and longer guides.

All resources are based on evidence-based practices that help support mind, body, and spirit throughout the cancer journey. Pocket guides and longer guides cover the major barriers to and aspects of cancer treatment (full list included on page 9).
While the need for whole person cancer care and the evidence supporting it exists, there are many challenges to implementing this new approach.

The IOLC faced the following challenges and learned the following lessons about making whole person cancer care routine.

**Patients’ fear of cancer can be a barrier to integrative oncology.**
Patients who are diagnosed with cancer are scared and overwhelmed. This makes it more difficult for them to consider adding complementary and lifestyle therapies to conventional cancer care. Most patients accept the current focus on killing cancer cells.

By including the patient voice and establishing the Patient Advocacy and Empowerment Collaborative, the IOLC learned more about the experience and needs of cancer survivors. The IOLC, with the help of the Patient Advocacy and Empowerment Collaborative, developed new resources for patients. Participating oncology care teams began to explore better ways to approach patients about integrative oncology services.

**Many barriers to implementing integrative oncology exist within health systems.**
Even though many oncology care teams and hospital systems want to incorporate integrative oncology, there are barriers within the systems that make this difficult. These barriers include:

- Integration in electronic health records,
- The need for a new workflow and new staff roles,

**Integration in electronic health records**
Many oncology care teams in the IOLC worked with their information technology teams to embed the PHI and the HOPE note into Epic, often using smart forms. Some developed reports to analyze aggregate responses.

**A new workflow and staff roles**
Implementing integrative oncology requires a new workflow for reaching out to patients and following up with them. Patients want to hear about integrative oncology from their oncologists, and many oncologists want to provide their patients with these services. But oncologists do not have the bandwidth to teach patients about integrative oncology.

Oncologists can introduce patients to integrative oncology and then have nurse navigators or social workers follow up and serve as the primary contact. The Ann B. Barsinger Cancer Institute is using advanced practice nurses as the primary contact for patients and their families.

**Oncology care teams and patients need an easy way to learn about and use integrative oncology.**
The IOLC developed cancer-focused tools to make it easier for oncology care teams to deliver whole person cancer care and resources such as pocket guides to help patients understand how integrative oncology services can help them heal.
The best time to approach patients about integrative oncology has yet to be determined. Patients should have access to integrative oncology services soon after being diagnosed, but this should not be discussed at the appointment when they are diagnosed with cancer. The best time to approach patients still needs to be determined.

The Ann B. Barsinger Cancer Institute expects to contact patients toward or at the end of active treatment. The survivorship and wellness team informs patients that a recovery phase will follow the active treatment phase, and that a member of the team will reach out to them about integrative oncology services. The team is working with information technology staff to automatically identify patients who are ready to schedule a wellness–survivorship care visit and automate the process.

Change is difficult. Oncologists do not learn the implementation science of change in medical school. Doing business as usual is easier than implementing a new approach.

In changing processes and systems, members of the IOLC learned the importance of:
- Emphasizing how the change will benefit oncology care teams and patients.
- Trying new things.
- Learning from what others are doing.
- Being patient.

Dr. Oyer developed a vision for transforming the survivorship program at the Ann B. Barshinger Cancer Institute into an approach focused on survivorship and wellness that allowed members of the oncology care team to see their role in achieving the vision. The vision and regular discussions helped the team understand and buy into the new approach.

Learning from other members of the IOLC made it easier for oncology care teams to try new things. They were able to try things that had worked for others and learned from others how to overcome challenges.

Implementing a big change takes time. Oncology care teams should be patient and focus on making progress in implementing whole person cancer care.

Billing and reimbursement systems do not pay for most integrative services. Cost is a barrier for patients to many integrative oncology services. Group medical visits and services supported by philanthropy are two ways to provide these services with little or no out-of-pocket costs to patients.

Group medical visits enable cancer centers to generate revenue from integrative oncology services while also serving patients faster. The Sidney Kimmel Cancer Center at Jefferson Health started a three-part group medical visit during the IOLC.

The Inova Schar Cancer Institute’s Life with Cancer program provides free integrative oncology services, funded by philanthropy (50%) and by the health system (50%).
Benefits of the Integrative Oncology Leadership Collaborative

The work of the IOLC benefited both the participating cancer centers and integrative oncology in general.

**BENEFITS FOR CANCER CENTERS**

Benefits for the participating cancer centers include:

- New thinking about and new approaches to integrative oncology.
- Streamlined delivery of whole person cancer care.
- A community of practice.

**A New Approach to Integrative Oncology**

Oncology care teams at the participating cancer centers developed new thinking about and new approaches to integrative oncology. This enabled them to develop new services or programs or enhance the work they were already doing.

For example, Dr. Oyer credits the shift from survivorship to survivorship and wellness at the Ann B. Barshinger Cancer Institute to his team’s participation in the IOLC. “It’s a totally different approach,” he says. “We probably wouldn’t have been able to do this if the Integrative Oncology Leadership Collaborative hadn’t changed our thinking.”

The team at the Sidney Kimmel Cancer Center at Jefferson Health used what it learned to develop a group medical visit program for cancer patients.

**Streamlined Delivery of Whole Person Cancer Care**

The participating cancer centers used tools and processes from the IOLC to begin to streamline the delivery of whole person cancer care.

The HOPE for Cancer Care tools, pocket guides, and other resources facilitated the delivery of whole person cancer care. The implementation plans the teams developed and the PDSA studies they conducted to evaluate their changes and plan next steps helped focus their work and move toward making whole person cancer care routine.
“By structuring a quality improvement effort [the PDSA studies] within their centers, it begins to change their system to make whole person cancer care easier to do,” says Dr. Jonas.

A Community of Practice

The IOLC provided a laboratory and a safe space for oncology care teams to learn from each other. “This became a community of practice—people with a shared passion who wanted to figure out how to do integrative oncology better by learning from each other,” says Dr. McManamon.

Participants learned from their peers what works and what does not in delivering whole person cancer care. They discussed common challenges and how other oncology care teams had solved them. When oncology care teams presented and discussed their work with the group, they got feedback and encouragement to keep moving forward.

Highlighting the role of all team members

Although oncologists must buy into and be involved with integrative oncology, other team members will be doing most of the work. The IOLC gave voices to and highlighted the roles of other members of oncology care teams, such as nurse navigators, social workers, and acupuncturists.

“Physicians alone cannot make things happen. Implementation requires a team. With a team anything is possible,” says Dr. McManamon.

BENEFITS FOR INTEGRATIVE ONCOLOGY

The IOLC highlighted that it is possible to make whole person cancer care routine and that oncology care teams can teach patients how this approach can help them heal.

The work of the collaborative can help shift the mindset of people who are diagnosed with cancer from focusing solely on killing cancer cells to healing through the use of complementary and lifestyle therapies that support conventional cancer care. “People will realize that they have quite a bit of control over their quality and quantity of life if they access integrative oncology services,” says Dr. Jonas.
Ongoing Work to Make Whole Person Cancer Care Routine

NEW GUIDELINES FOR AND KNOWLEDGE ABOUT INTEGRATIVE ONCOLOGY

To help oncologists learn how to deliver whole person cancer care, the Society of Integrative Oncology and ASCO are developing joint clinical guidelines. The first of these, *Integrative Medicine for Pain Management in Oncology: Society for Integrative Oncology–ASCO Guideline*, was published in 2022. Four additional guidelines are under development and are expected to publish in 2023 and 2024.

While the IOLC ended in December 2022, work to make whole person cancer care routine continues. In January 2023, Dr. Wayne Jonas launched a new organization whose mission includes innovation in whole person cancer care. Jonas’s new organization, the Healing Works Foundation, continues to gather, refine, and share tools for integrative oncology.

Tracking Integrative Oncology and Focusing on the Patient Perspective

An annual survey of cancer centers and patients, with IQVIA, will enable the Healing Works Foundation to track what is happening in integrative oncology. Leyh will continue to consult with the Healing Works Foundation on the patient’s perspective on integrative oncology.

NATIONAL DIALOGUE AND DISSEMINATION

The Healing Works Foundation also plans to work with national bodies to make integrative oncology and whole person cancer care part of the national dialogue around cancer care and to disseminate tools, guidelines, and resources.

The National Cancer Moonshot

The federal Cancer Moonshot seeks to reduce the cancer death rate by half within 25 years and improve the lives of people with cancer and cancer survivors. Many of the goals of the Cancer Moonshot are aligned with whole person cancer care and the work of the IOLC.

“By continuing to do this work, I hope that whole person cancer care and integrative oncology will rise to the level of national discussion and be considered when policy and payment decisions are made.”

—Wayne Jonas, MD

Dr. Jonas has presented the work of the IOLC to the administration and would like to collaborate with them on the Cancer Moonshot to incorporate whole person cancer care.
NEXT STEPS FOR PARTICIPANTS

The cancer centers that participated in the IOLC continue their work to make whole person cancer care routine. They are using the tools developed during the collaborative and what they learned from other oncology care teams to develop approaches and processes to deliver whole person cancer care. Also, they are sharing the patient resources with their patients.
Conclusion: Whole Person Cancer Care Helps Patients Live Longer, Better, and with Less Fear

The IOLC showed that it is possible to make whole person cancer care routine.

Healing from cancer takes more than eliminating the cancer. Whole person cancer care offers a way to support conventional cancer care by empowering and engaging patients to take an active and preventive role in their health. It focuses on what matters most to the patient and integrates each patient’s personal determinants of healing into their cancer care.

Using evidence-based complementary and lifestyle therapies such as nutrition, meditation, exercise, acupuncture, and yoga helps patients activate their individual ability to heal as they go through cancer treatment and into survivorship and thivership.

PATIENTS WANT HELP WITH COMPLEMENTARY AND LIFESTYLE THERAPIES

Patients are increasingly using complementary and lifestyle therapies to combat the side effects of cancer care and help restore their quality of life. They want support from their oncologists and cancer centers in using whole person cancer care.

CANCER CENTERS CAN DELIVER WHOLE PERSON CANCER CARE

Oncology care teams at cancer centers can deliver whole person cancer care. The teams participating in the IOLC showed this. They:

- Used the integrative oncology tools they helped develop to help patients heal.
- Developed new approaches and processes to effectively and efficiently deliver whole person cancer care.

“These innovative changemakers need a forum to problem solve, learn from each other, and explore different ideas. The Integrative Oncology Leadership Collaborative gave them an opportunity to share challenges, barriers, and solutions.”

—Jenny Leyh
WHOLE PERSON CANCER CARE CAN BECOME ROUTINE

Whole person cancer care empowers patients to survive and to thrive. Patients who receive whole person cancer care can live longer, better, and with less fear.

Making whole person cancer care routine in cancer care is possible. The IOLC has started doing this.

These practices used in the IOLC are in alignment with the newly released (September 2022) joint practice guidelines from the Society for Integrative Oncology and ASCO regarding treatment of pain within cancer care.
The IOLC helped oncology care teams make whole person cancer care routine. Participants from 13 cancer centers and two other organizations currently offering integrative oncology or some facets of whole person care created, tested, and refined a set of tools for delivering whole person cancer care. The tools streamline the delivery of whole person cancer care. Each cancer center team also developed and began implementing a plan to use the tools.

HOW THE INTEGRATIVE ONCOLOGY LEADERSHIP COLLABORATIVE WORKED

Participants in the IOLC included practicing oncologists with formal training in integrative oncology and those with strong academic interest in the field but no formal integrative training. Participants reviewed and discussed the current state of the science, gaps, and future opportunities in whole person cancer care. They:

1. Attended monthly web-based sessions.
2. Provided feedback on the HOPE for Cancer Care tools and other whole person cancer care resources drafted by the team.
3. Tested these tools and other resources in their centers to refine them for routine use.
4. Developed an implementation plan to use the tools and presented their progress and challenges to the group.
5. Interacted regularly with a related patient advisory group to understand the patient perspective more fully.
6. Were encouraged to identify team members from their workplace to participate with them in the IOLC.
7. Supported and learned from each other.

SAMUELI FOUNDATION

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PARTICIPANTS

Cancer Centers

- Ann B. Barshinger Cancer Institute, Lancaster General Hospital, Penn Medicine
- Carrillo Kern Center for Integrative Therapies, Sentara Integrative Therapy Center, Sentara Health
- Davidoff Cancer Center, Rabin Medical Center, Israel
- DeCesaris Cancer Center, Luminis Anne Arundle Medical Center
- Inova Schar Cancer Institute, Life with Cancer
- James M. Stockman Cancer Institute, Frederick Health
- Johns Hopkins
- Karuna Precision Wellness Center
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References


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