



NCBGH Oncology Roundtable

NORTH CAROLINA BUSINESS GROUP ON HEALTH

Module 3: Survivorship, Surveillance & Back to Work

National Alliance Oncology Initiative



Module 3: Survivorship, Surveillance & Back to Work

Discussion Items

A. Advance Care Planning

- Health Care Wishes
- Palliative Care
- Hospice

B. Survivorship, Surveillance & Return to Work

- Supporting the Patient Journey at the Workplace
- Surveillance
- Return to Work
- Caregiving

C. Update on Hot Topics

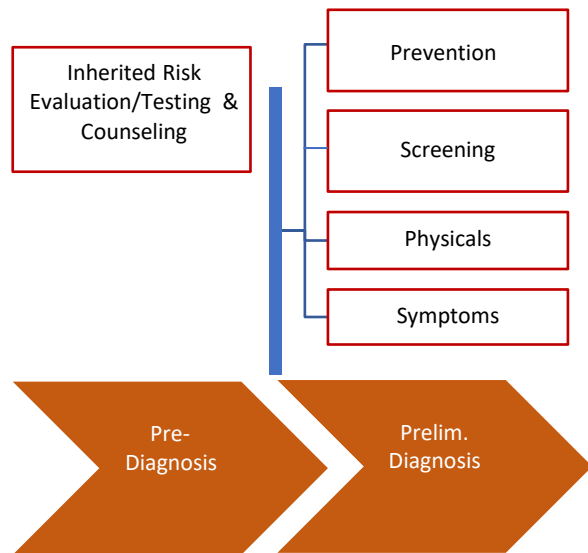
- Payment reform
- Impact of Covid-19

NOTE: Definitions of key terms and acronyms can be found in the Glossary at the end of this presentation

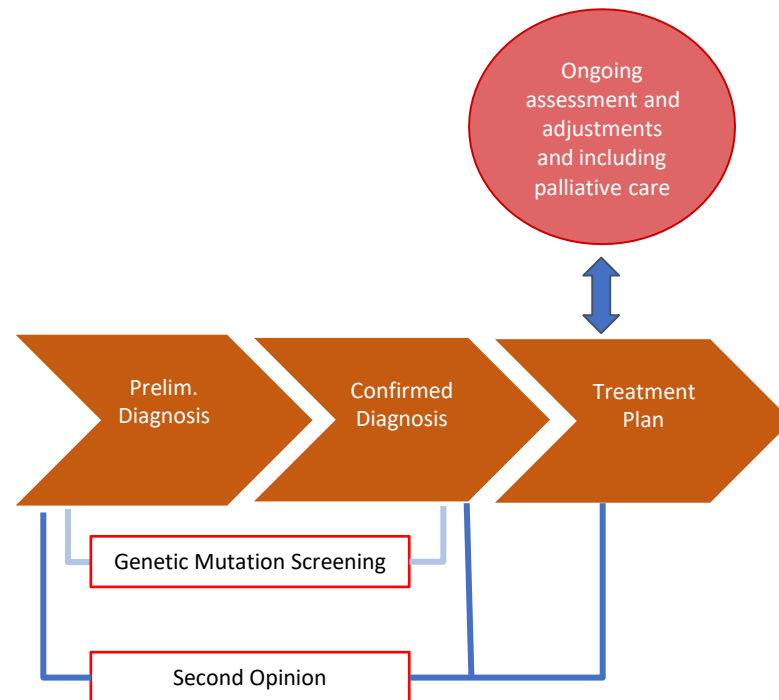
Specific Learning Modules

Zeros in on Different Components of the Patient Journey

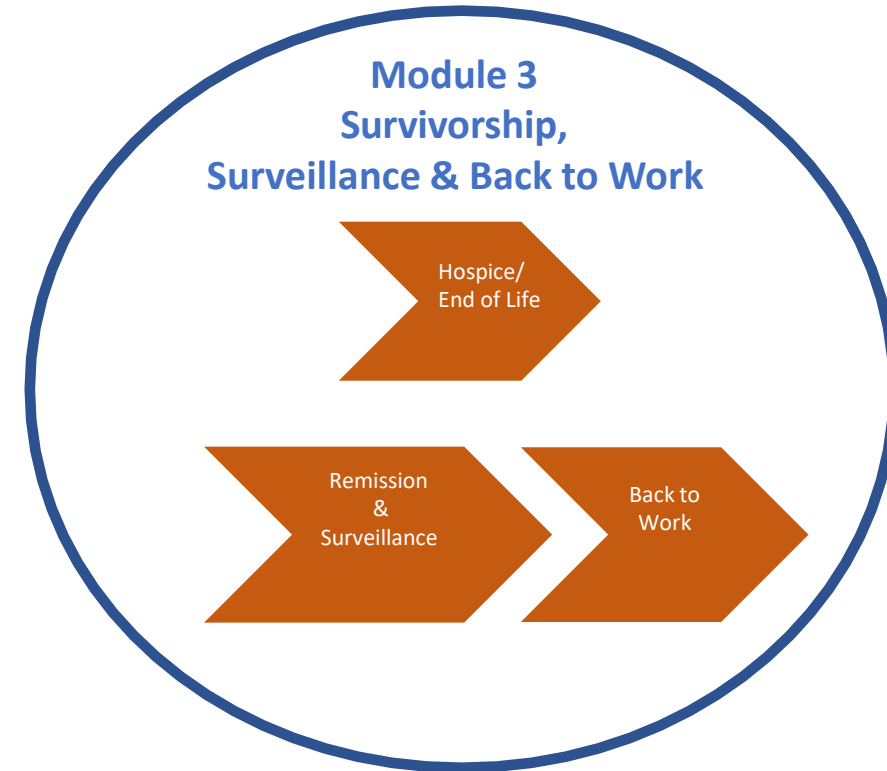
Module 1 Prevention & Preliminary Diagnosis



Module 2 Diagnosis, Treatment Planning & Care



Module 3 Survivorship, Surveillance & Back to Work



Need for patient & caregiver psychosocial support, coordination, accommodation & benefits education across the journey

Advance Care Planning

Most Should be Addressed at the Start of the Journey, if not Before

“Advance care planning” is making decisions in advance about how to deal with a medical crisis and includes:

- Advance Directive
- Medical Power of Attorney (or Health Care Proxy)
- Durable Power of Attorney

Value increases if plan is in place **before** any cancer or non-cancer treatments

- Difficult to make decisions in the stress of the moment
- Ensures adherence to individual preferences
- Can relieve family of difficult decisions

ADVANCE DIRECTIVE

a written statement of a person's wishes regarding medical treatment, often including a living will

MEDICAL POWER OF ATTORNEY/HEALTH CARE PROXY:

a document in which an individual designates another person to make health care decisions if he or she is rendered incapable of making their wishes known

DURABLE POWER OF ATTORNEY:

a document that allows an individual to make bank transactions, sign Social Security checks, apply for disability, or simply write checks to pay the utility bill while an individual is medically incapacitated

Advance Care Planning

Studies Show it's Often Deferred Too Long

Only 1/3 of those < age 45 had some form of legal document in place

- Among those aged >45, between 29% and 46% had not completed even one

Respondents from all age groups had widespread misconceptions about palliative and hospice care

Source: CancerCare Patient Access and Engagement Report. New York: CancerCare; 2016, p.9

When to re-examine your health care wishes:

1. Start of a new decade of life
2. A loved one dies
3. Divorce or other family upheaval
4. A serious diagnosis
5. Significant decline in health condition
6. Move to a new residence or someone moves in with you

Source: American Bar Association, Commission on Law and Aging, *Tool Kit for Health Care Advance Planning*

Advance Care Planning

The Institute of Medicine found Wide Variations in Individual Wishes

- African Americans are less likely than white non-Hispanics to express any treatment wishes or to have written advance care planning documents.
- White Protestants (72%), Catholics (65%), and Evangelicals (62%) *would stop medical treatment* if they had an incurable disease and were suffering a great deal of pain
- Most black Protestants (61%) and Hispanic Catholics (57%), wanted their physician to “*do everything possible to save their lives*”
- More than 81% of U.S. patients with head and neck cancers wanted to hear the diagnosis alone, but patients from family-centered cultures (e.g., Japanese) more likely want a relative present
- Most (84%) of Latinos aged 60+ from L.A. would prefer care focused on relieving pain and discomfort if they became seriously ill, yet nearly half (47%) had never discussed these preferences with either their family or their physicians

Source: National Academy of Sciences. All rights reserved. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life, 148-154 (2015)

Advance Care Planning

What Employers Should do

Educate entire workforce (not just cancer patients)

- Explain what it is
- Raise awareness of importance
- Make resource materials available
- Identify/refer to local resources
- Recognize differences across populations

Potential sources of assistance

- HR
- EAP
- PCP, hospital, other providers
- Attorneys, consumer organizations

Advance Care Planning Resources

AARP

<https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/>

American Bar Association

https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning/

Cancer Support Community

<https://www.cancersupportcommunity.org/radio-show/spotlight-metastatic-breast-cancer-advanced-care-planning>

National Hospice and Palliative Care Organization

<https://www.nhpco.org/>

Palliative Care & Hospice

Enhancing the Patient Experience

- Patients often confuse “palliative care” with “hospice”
- Both involve *treatment of symptoms* often associated with Cancer to improve quality of life
 - Pain
 - Gastrointestinal symptoms
 - Challenges getting enough nutrition and hydration
 - A wide range of other symptoms
- Both include caregiver support, including respite care
- Major differences:
 - hospice requires ≤ 6 mos. life expectancy
 - Palliative care allows treatment with curative intent – hospice does not
 - Hospice provides strong care coordination for hospice-specific services
 - there is well-defined benefit language for hospice; less so for palliative care

Palliative care... is specialized medical care that focuses on providing patients relief from pain and other symptoms of a serious illness, no matter the diagnosis or stage of disease. Palliative care teams aim to improve the quality of life for both patients and their families. This form of care is offered alongside curative or other treatments you may be receiving.

[Source: Mayo Clinic]

Hospice care... is a special kind of care that focuses on the quality of life for people and their caregivers who are experiencing an advanced, life-limiting illness. Hospice care provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible.

[Source: American Cancer Society]

Palliative Care & Hospice

Differences in Scope of Benefits

Most health plans offer hospice benefits patterned on the Medicare Hospice Benefit

- May limit # days
- Typically contracts per diem % of Medicare

No standard “Palliative Care Benefit” per se:

- Medicare pays for elements of palliative care that it covers individually
- Typical employment-based plans cover services, when taken together can make up palliative care

Example of Hospice Benefits (Medicare)

In home or an inpatient facility...

- Doctor services
- Nursing care
- Medical equipment (like wheelchairs or walkers)
- Medical supplies (like bandages and catheters)
- Prescription drugs
- Hospice aide and homemaker services
- Physical and occupational therapy
- Speech-language pathology services
- Social worker services
- Dietary counseling
- Grief and loss counseling for you and your family
- Short-term inpatient care (for pain and symptom management)
- Short-term respite care
- Any other Medicare-covered services needed to manage your terminal illness and related conditions, as recommended by your hospice team

Source: CMS Medicare Hospice Benefits

Palliative Care & Hospice

Enhancing Quality of Life Near the End of Life

How palliative care and hospice can help

- Managing symptoms – physical & mental
- Providing information about changes one might experience as the illness progresses
- Guiding families in giving care and support to their loved one
- Offering emotional support to individuals and their families
- Preventing hospitalizations with a nurse available any time, day or night
- Making bereavement support available to families in a variety of ways

When is hospice is brought up for discussion:

- When the doctor says there are no more treatments
- Second line: case manager might bring it up
- When the patient says “I’m done”

Palliative Care & Hospice

What Employers Should Do

- Educate your work force about Palliative & Hospice Care
- With your health plan:
 - Formulate a palliative care benefit; or
 - Identify existing covered benefits that can make up a palliative care approach
- Make sure:
 - Your health plans cover Palliative & Hospice Care, including caregiver support
 - Your health plans cover Palliative & Hospice Care providers in their networks
 - High-quality palliative care services are offered to cancer patients as early as possible by the treating physician, cancer center, or health plan
- Require health plans to collect data* on events near the end of life including:
 - ER visits by cancer patients enrolled in hospice
 - Proportion in hospice for less than three days

Aetna's Compassionate Care Program

Among commercial health plan members, the program led to a more than doubling in hospice use as well as an increase in hospice lengths of stay (13 to 15 days longer). Extending hospice benefits to 12 months did not result in increased costs compared to those without extended hospice benefits.

Source:

<https://www.commonwealthfund.org/publications/case-study/2018/may/profiles-promise-advanced-illness-management>

*Source: Core Quality Measures, Developed by the Core Quality Measures Collaborative, led by the America's Health Insurance Plans (AHIP) and its member plans' Chief Medical Officers, leaders from CMS and the National Quality Forum (NQF), as well as national physician organizations, employers and consumers.

Survivorship, Surveillance & Return to Work

Growth in Survivorship → New Demands on Employers

Cancer survivorship is projected to increase by 25% to 30% during the 10 years ending in 2026

As a result, employers will find that more of their employees:

- Need to adhere to periodic surveillance protocols
- Are caregivers for others with cancer
- Can benefit from survivorship plans

These trends cause new, increasing demands on employers



Survivorship, Surveillance & Return to Work

Identify New Roles for EAP or Seek Support from Outside Agencies

Training & seminars

- Prevention, Screening & Advance Planning for entire workforce – before the Patient Journey
- Worksite accommodation during and after Patient Journey
- Awareness of disability coverage

Intake & referral (if not otherwise provided by provider or health plan), e.g.,

- Psychosocial, navigational, financial, other support during Patient Journey
- Specialized services CoE, hospice

Support for challenging cases

- Employees (& families) facing bad outcomes

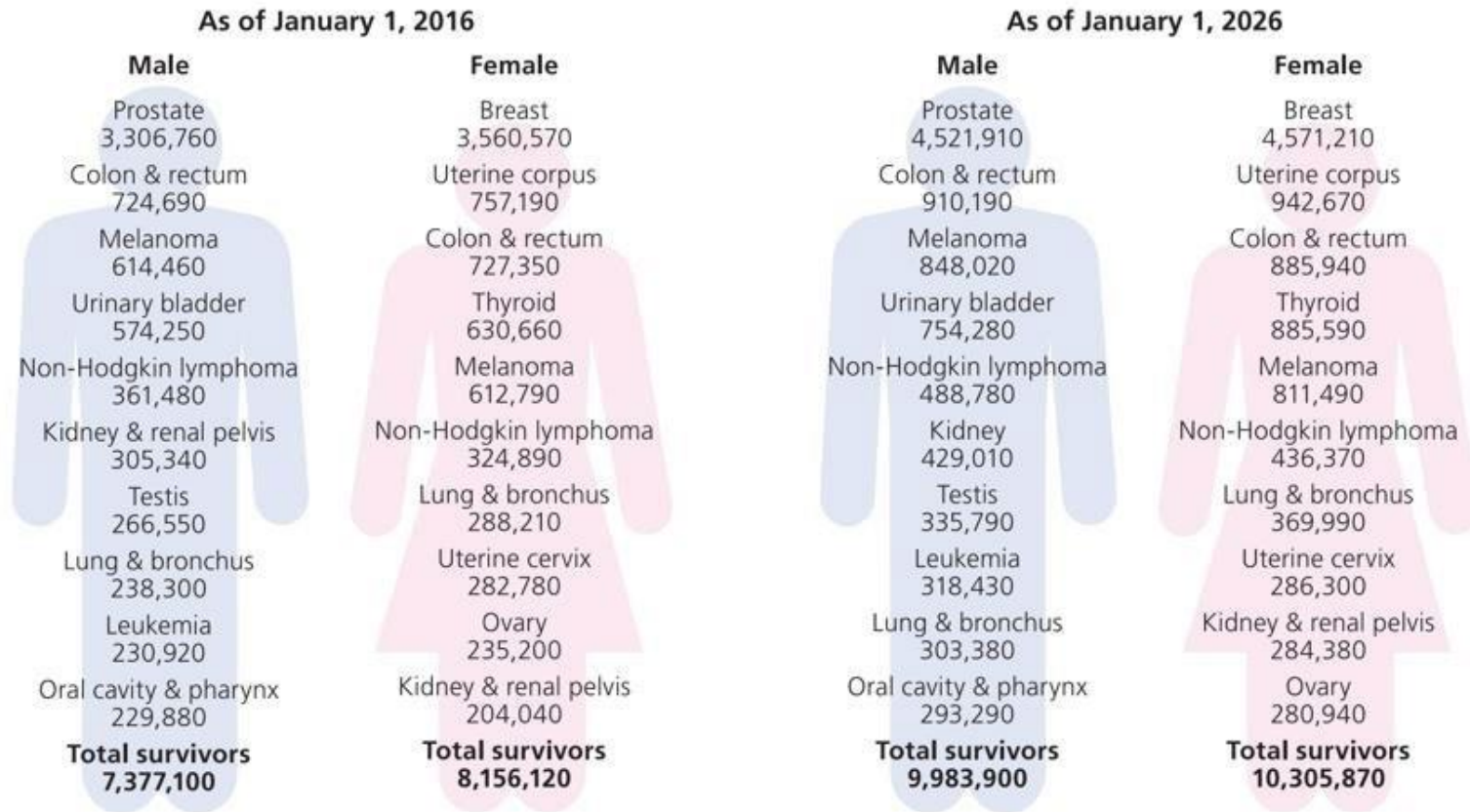
Support managers addressing employees' needs, including survivorship & return to work



Increasing Survivorship Drives Increase in Need for Surveillance

Employers Should Develop a Value-Based Approach

Projected Number of Cancer Survivors by Tumor Site (2016-2026)*



*Source: MD Anderson Cancer Center

National Alliance- PCORI Engagement (2019)

Cross-National Study of Colorectal Cancer Surveillance

Study found:

Intensification of surveillance has a negligible impact on the detection of recurrence or survival

- May slightly increase rate surgery for distant recurrence
- No need to image more frequently than once/year
- Earlier stage patients may require less follow-up

Follow-up care should emphasize

- Management of treatment associated toxicity
- Health promotion and secondary prevention
- Psychosocial well-being

Health Benefits RESEARCH REVIEW
Current research findings of interest to health benefits plan professionals

CANCER CARE SURVEILLANCE
How frequently should cancer survivors be monitored for disease recurrence? Is more always better?

EMPLOYER INSIGHTS
Our discussions with the National Alliance Medical Director Advisory Council suggest the following is a key finding in cancer surveillance:

- 1. More frequent surveillance for cancer recurrence is a costly process, and intensification of the surveillance process is not always needed by many patients. Following and meeting performance objectives will require the benefits of cost-effective care.
- 2. The appropriate frequency of surveillance should be based on the severity of the disease and the patient's health status. This is an important question for employers that will help determine if and when surveillance benefits and costs will be most valued by the patient.
- 3. The quality of surveillance care is more important than the frequency of surveillance. This can be achieved through quality improvement efforts, training of the clinical staff, and investment in reporting and data systems. Consider a patient-centered approach to surveillance through the employer.
- 4. Surveillance efforts by employers need to be supported by primary and secondary prevention services and other patient-centered care services.

What's the issue?
Every year 12.1 million cancer survivors in the United States with numbers expected to rise to 20.5 million by 2020. They typically face the same issue: how often to monitor and test for recurrence of their past cancer type. But increasing surveillance frequency may have a negligible impact on employer health care costs, symptoms to patients and quality of life, and workforce well-being.

What did the PCORI-funded study do?
This publication focuses on recent findings from a study funded by the Patient-Centered Outcomes Research Institute (PCORI) about the frequency of testing following prostatectomy surgery for colorectal cancer, addressing the question: whether more frequent testing was better at lowering 5-year recurrence rates for prostate cancer.

What were the results and their potential impact?
The PCORI-funded study found that healthcare facilities that do more frequent surveillance did not detect recurring cancers any earlier than facilities that do less frequent surveillance, suggesting more frequent testing provided no health benefit.

Frequency of Surveillance	5-Year Recurrence Rate	Cost per Patient
Less frequent surveillance	~10%	~\$1,000
More frequent surveillance	~10%	~\$1,500

In addition to these higher frequencies, the study found that costs related to more frequent surveillance were not reduced for patients.



“This PCORI-funded study found that healthcare facilities that do more frequent surveillance did not detect recurring cancers any earlier than facilities that do less frequent surveillance, suggesting more frequent testing provided no health benefit.”

George J. Chang, MD, MS; The Alliance for Clinical Trials in Oncology Foundation

Increasing Demands on Caregivers can Impact Employers

Needs Often Ignored

Employees who are the patient may require support from family or other caregivers

Employees may be caregivers and require time off to fulfill this role

Work accommodations for caregivers

- Telecommuting
- Flex time
- Use of sick time and other paid and unpaid time off

It is important for the patient and caregiver to have access to as much support as possible

- Educational materials
- Financial support
- Care coordination
- Clear understanding of the benefits available through all benefit lines – medical, behavioral health, EAP, specialty vendors

Checklist of Caregiver Needs

- Identify wide range of friends and others who can help with these services
- Identify services available through employer programs such as EAP
- Use respite services if available
 - Home health aid
 - Respite care facility
 - Private duty nurse

Planning for Increased Survivorship

What Employers Should Do

Plan for the impact of increased cancer survivorship on their organization:

- Develop support resources, whether EAP or external organizations, specifically to:
 - Support appropriate surveillance adherence
 - Consider the needs of employee caregivers
- Encourage Survivorship Planning

The image shows two forms from OncoLife, a survivorship care plan program from Penn Medicine. The top form is a navigation menu with tabs for HCP FAQs, Survivor FAQs, References, Publications, Editorial Board, Feedback, and OncoLink. Below the menu is a timeline with seven numbered points: 1. Care Plan Version, 2. Demographics, 3. Cancer Types, 4. Surgeries, 5. Chemotherapy and Biologic Therapies, 6. Radiation Therapy, and 7. Side Effects. The bottom form is a 'Treatment Summary' form for prostate cancer, including sections for Diagnosis (Stage, Gleason Score, Clinical Trial, PSA at Diagnosis), Treatment Completed (Survival Date), Treatment Ongoing (Need for ongoing treatment, Additional treatment name, Planned duration, Possible Side effects), Follow-up Care Plan (Coordinating Provider, Schedule of Clinical Visits), and Cancer Surveillance or other Recommended Tests (Coordinating Provider, Test, How Often).

Sources:

OncoLink: <https://oncolife.oncolink.org/>

ASCO: <https://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans>

Discussion of Payment Reform

Progress has been Slow

There have been attempts to reform payment based on bundled payment

These have largely failed for a number of reasons:

- The incidence of cancers is fairly low. For example, there are about 280,000 cases of breast cancer (the most common cancer) predicted for 2020. That's about 1 per every 1100 population.
- The severity of the disease within a cancer type can vary markedly.
- The prevalence of any specific cancer in a population is relatively small
- Prognosis and therapy varies by the patient's underlying risk factors and other conditions
- Over the past few years there has been rapid development of biomarkers and biomarker specific therapies. These may affect a small percentage of patients but can drive much higher costs.
- The diagnosis of cancer raises emotional concerns and demand for more flexibility in the choice of treatment center. This makes managing volume commitments to a specific center more difficult.

Bottom line – the relatively low incidence, the complexity of the disease, and the variation in treatments makes the usual payment reform methods unworkable.

Extension of care over a period longer than one-year term of health insurance can also be a challenge

Medicare Oncology Payment Model (OPM)

Begun in 2016 as a 5-year CMS Innovation Center Program

Based on FFS program with additional payment for enhanced services

- The core functions of patient navigation;
- A care plan that contains the 13 components in the Institute of Medicine Care Management Plan outlined in the Institute of Medicine report, “Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis”;
- Patient access 24 hours a day, 7 days a week to an appropriate clinician who has real-time access to practice’s medical records; and
- Treatment with therapies consistent with nationally recognized clinical guidelines.

Sets quality standards

The Performance-Based Payment was calculated retrospectively on a semi-annual basis based on the practice’s achievement on the OCM Quality Measures and reductions in Medicare expenditures below a target price.

<https://www.cms.gov/newsroom/fact-sheets/oncology-care-model>

Medicare Oncology Payment Model (OPM)

Year 3 Report

Financial

- No significant impact on overall payment
- Net loss to Medicare when payment for enhanced services are included
- No reductions in use of novel treatments
- No increase in efficiency

Quality

- Improved care coordination with 24/7 access
- Expanded financial counseling
- No change in ER visits or hospital admissions
- No change in chemotherapy toxicity events
- 1.1% decrease in hospital admissions at the end of life

Bottom line “Little Evidence of Value-Oriented Changes in Therapeutic Approach. There is little evidence that OPM is driving value-oriented selection of chemotherapy regimens, supportive care medications, or radiation therapy treatment. “

Payment Innovation

Initial Steps

While payment methods for other conditions such as care bundles or capitation may not be feasible for cancer there are other tactics that can manage expense

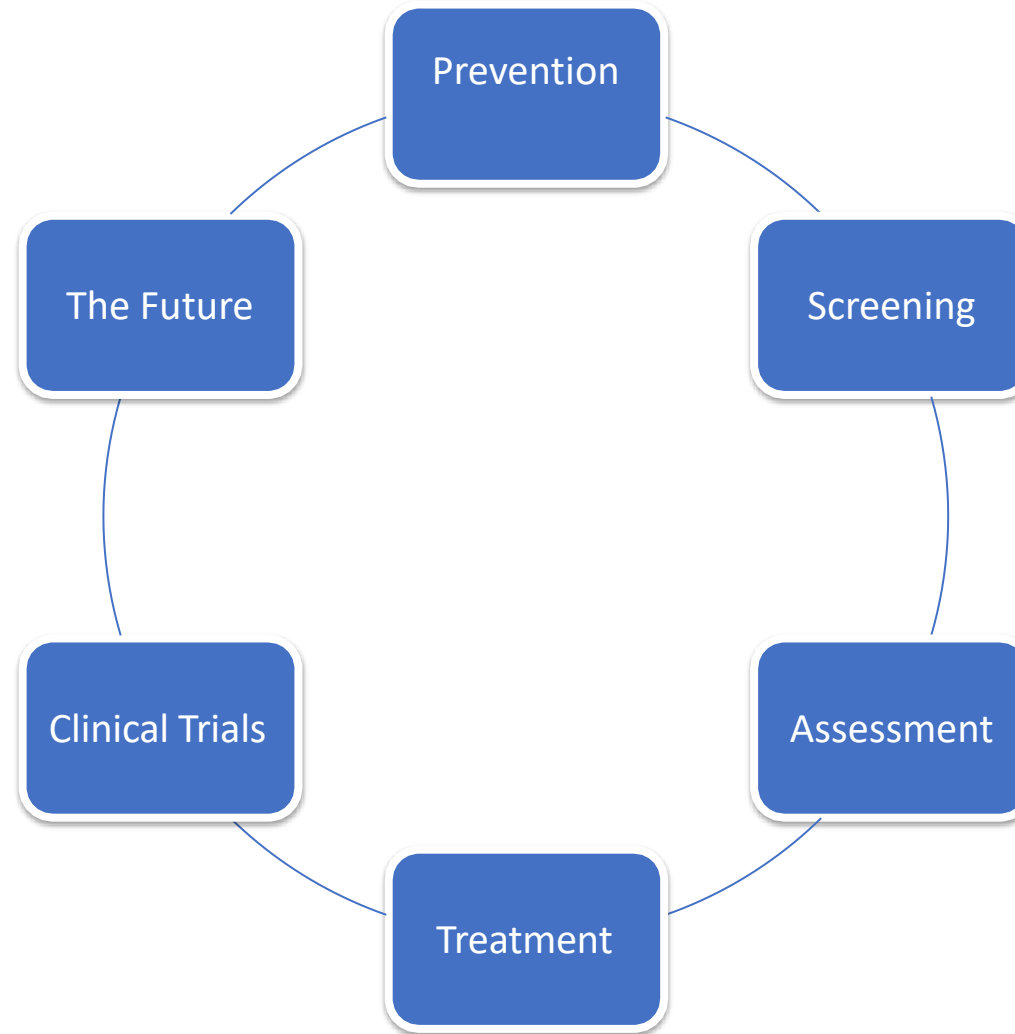
- Bundle chemotherapy costs to include the drug, infusion and site of care costs
- Value Based Pharmacy, especially for the newer high-cost drugs
- Steer patients and/or require the use of lower cost care centers such as outpatient infusions or even home infusions where appropriate
- Identify high value providers
 - Adhere to standard guidelines
 - Provide care in the most efficient settings
 - Provide care navigation and coordination
 - Provide comprehensive support for patients and families

Overall, value-based contracting for biopharmaceuticals is in its early stages, and the consensus among expert panels convened by NEHI is that thoughtful experimentation in these contracts should proceed.

Source: <https://www.nehi.net/publications/79-value-based-contracting-for-oncology-drugs-a-nehi-white-paper/view>

Impact of COVID-19

Impact all Along the Cancer Patient Journey



Impact of COVID-19

Prevention, A Mixed Bag

Social isolation has given people more time for video tools

- Education/advice for prevention
- Treatment for risk factor: diet, smoking, alcohol

Isolation and stress increase risk may increase risky behaviors and limit positive ones

- Smoking
- Alcohol use increase
- Lifestyle changes more challenging
- Healthy food choices
 - Could go either way – decreased restaurant food, but more canned and frozen foods and other foods that may have high salt and fat
 - Exercise – may be up despite restrictions on gyms and being outdoors
- Weight loss

Unintended Consequences?

The virus has caused so many changes in our daily lives. ...

...might this offer an opportunity to change some habits for the better: eating, exercise, etc.?

Impact of COVID-19

Screening

Concerns about virus exposure limit screening such as mammography, skin exams, pap smears.

Colon cancer screening deferred because of risks to providers and patients.

Cancer screening down 86-94% based on data from Epic

- Worth noting that screening schedules are set on an annual or greater periodicity, so delays of months will probably have little effect on overall rates once the backlog can be processed

In response to the coronavirus disease 2019 (COVID-19) pandemic, the U.S. Surgeon General advised all hospitals and ambulatory care centers to delay nonurgent medical procedures and surgeries. ...gastroenterologists, patient advocates, and colorectal cancer (CRC) researchers have witnessed the downstream impact of COVID-19 and this recommendation on CRC screening, research, and advocacy.

These effects are particularly noticeable in medically underserved communities where CRC morbidity and mortality are highest. COVID-19–related pauses in medical care, as well as shifts in resource allocation and workforce deployment, threaten decades worth of work to improve CRC disparities in medically underserved populations.

Source: Gastrointest Endosc 2020;-:1-5.

Impact of COVID-19

Treatment

- Current or past patients with cancer are at increased risk from the virus.
- Treatments (surgery, chemotherapy, radiation) increase risk by decreasing the immune response.
- Social distancing for most cancer care is impossible - infusions, surgery, etc.
- The priority for care of COVID patients has limited the availability of beds, operating rooms, ventilators, personal protective equipment and other resources necessary for the care of some patients and the protection of the cancer care staff.

According to Flatiron Health's analysis of medical record data:

- 13% fewer scheduled chemotherapy infusion visits were fulfilled
- 33% drop in daily non-infusion visits
- 60% increase in appointment cancellations
- 50% decrease in new patient visits

Impact of COVID-19

Treatment (continued)

Not all cancer types or clinical picture pose the same acute risk.

- Treatment for many conditions can be safely delayed for a few months with very low risk.

Specialty societies have developed recommendations for treatment based on which tumor types and findings need acute care and which can wait with minimal risk

In addition to the risk stratification and risk-benefit issues, local conditions need to be taken into consideration:

- Where in the course of epidemic is the location?
- Are there beds available for all acute care?
- Is there adequate PPE, etc.?

Impact of COVID-19

Treatment (cont.)

Case Study (Netherlands): Changes to treatment processes

5,302 patients with cancer completed this nationwide survey

- Overall, 30% of patients reported consequences for their oncological treatment or follow up.
- Most common was a switch from in person to video visits.
- The most frequently adjusted treatments were chemotherapy (30%) and immunotherapy (32%).
- Among patients with delay and discontinuation of treatment, 55% and 63% of patients, respectively, were (very) concerned about these consequences of the COVID-19 pandemic

COVID-19 impact on future cancer deaths

Another study (UK): increased mortality

A study of 32,583 patients with breast cancer, 24,975 with colorectal cancer, 6,744 with esophageal cancer, and 29,305 with lung cancer developed three different scenarios, compared with pre-pandemic figures and estimated an increase in deaths over 5 years for a number of cancers.

Type of Cancer	Increase in Deaths
Breast Lung	+7.9–9.6%
Esophageal	+4.8–5.3%
	+5.8–6.0%

Source: Lancet Oncol 2020; 21: 1023–34, Published Online, July 20, 2020, [https://doi.org/10.1016/S1470-2045\(20\)30388-0](https://doi.org/10.1016/S1470-2045(20)30388-0)

Impact of COVID-19

Clinical Trials

All of the challenges for care apply to clinical trials with additional constraints

- Clinical trials of treatment other than oral medication require travel to a health care facility. There may be perceived and actual risks of doing so.
- Clinical trials require monitoring on a set schedule. Patients may be concerned about having imaging or blood tests.
- Delays in patient evaluation may threaten the validity and acceptability of the trial.
- Recruitment may be a challenge with the lack of face-to-face discussions.

Adapting to a pandemic - conducting oncology trials during the SARS-CoV-2 pandemic

Impact of COVID-19: *Forcing change*

Covid presented an opportunity for innovative service delivery

In order to avoid exposure to Coronavirus, more care has had to be delivered virtually. This has opened up new opportunities for more efficient care after the pandemic.

Assessment for initial care as well as for follow up can be partially completed virtually

- Evaluation of symptoms and even visual inspection of masses
- Review of previous testing
 - Testing and imaging must be performed in person but can be done at sites with limited exposure risk.
- Risk stratification, assessment of urgency and treatment planning
- Tumor boards

Treatment at home can often be done safely, even some infusions.

While most oncologists had not previously used virtual services, the current situation has resulted in significantly increased use.

The Moffitt cancer center (Tampa, Florida NCI Comprehensive Cancer Center) has increased virtual visits 5,000%.

<https://www.pennmedicine.org/updates/blogs/penn-physician-blog/2020/june/infusion-therapy-and-home-based-chemo-the-innovation-of-penn-cancer-care-at-home>

<https://www.cancer.org/treatment/treatments-and-side-effects/planning-managing/getting-treatment-at-home.html>

Thank You!



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References: Impact of COVID-19

- Overall impact: (<https://flatiron.com/blog/impact-covid-community/>)
- Increased risk of alcohol use: (https://healthcare.utah.edu/the-scope/shows.php?shows=0_p0xim6x3)
- Healthy food choices: (<https://time.com/5827315/coronavirus-diet/>)
- Exercise: (<https://time.com/5827315/coronavirus-diet/>)
- Screening: (<https://www.cancerhealth.com/article/routine-cancer-screenings-plunge-covid19>)
- Assessment: % (<https://moffitt.org/for-healthcare-providers/onco-update-provider-blog/onco-update-story-archive/virtual-oncology-visits-are-up-5-000-at-moffitt-are-they-here-to-stay-after-covid-19/>)
- Assessment: <https://nyulangone.org/news/new-suspicion-cancer-virtual-clinic-provides-consults-people-who-may-have-cancer-symptoms>

References: Impact of COVID-19 (cont.)

- **Annals of Surgical Oncology.** Management of Cancer Surgery Cases During the COVID-19 Pandemic: Considerations: (<https://link.springer.com/article/10.1245/s10434-020-08461-2>)
- **Radiation Oncology:** (<https://www.astro.org/Daily-Practice/COVID-19-Recommendations-and-Information/Summary>); The Impact of COVID-19 on Radiation Oncology Clinics and Patients With Cancer in the United States: (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7118653/>)
- **Clinical Trials:** <https://clincancerres.aacrjournals.org/content/early/2020/04/18/1078-0432.CCR-20-1364>
- **The Future:** (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7167574/>)

References: Impact of COVID-19 (cont.)

- **American Society for Clinical Oncology.** ASCO Guidance on Allocation of Scarce Resources During COVID-19 Pandemic: (<https://www.asco.org/asco-coronavirus-information/provider-practice-preparedness-covid-19>)
- **Virtual Tumor Board:** (<https://igcs.org/covid-19-virtual-tumor-boards/>)
- **Annals of Internal Medicine.** A War on Two Fronts: Cancer Care in the Time of COVID-19: (<https://www.acpjournals.org/doi/pdf/10.7326/M20-1133>)
- **American College of Surgeons.** Local Resumption of Elective Surgery Guidance: (https://www.facs.org/-/media/files/covid19/local_resumption_of_elective_surgery_guidance.ashx)

Glossary

Term	Definition (Source)
Advance Directive	A legal document containing written instructions about your future medical care if you become unable to speak for yourself. (1)
Advance Care Planning	Advance care planning is making decisions about the healthcare you would want to receive if you're facing a medical crisis. These are your decisions to make based on your personal values, preferences, and discussions with your loved ones. (2)
AHIP	America's Health Insurance Plans
AHQR	Agency for Healthcare Quality & Research
American Society of Clinical Oncology (ASCO)	Founded in 1964, the American Society of Clinical Oncology is the world's leading professional organization for physicians and oncology professionals caring for people with cancer. (3)
Approved off-label Rx	[Approval of] The use of a medication for a purpose other than the use approved by the U.S. Food and Drug Administration (FDA). The FDA approves drugs as safe and effective for specific uses, for example, use for colon cancer or breast cancer. More than half of the uses of anticancer medications are for indications which are not specified as approved and indicated on the label. Some insurance companies may deny coverage for a medication that is used "off-label." The federal government requires that Medicare cover these off-label uses for treating life-threatening conditions as long as certain requirements are met. This is true for many private insurers as well. (1)
ASCO	American Society of Clinical Oncology
Biomarker	A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition. Also called molecular marker and signature molecule. (4)
Biomarker Testing	Also called tumor profiling, genomic testing, mutation testing, or molecular testing. Looks for changes in the cancer's genes. Helps your doctor match targeted therapies to the specific subtype of cancer you have. A sample of your cancer is collected via bodily fluids, surgery, or biopsy and sent to a lab. Your test results can then be used to help guide your treatment options. For example, your biomarker test results will show if you're ALK+ in lung cancer, HER2+ in breast cancer, or BRAF+ in melanoma or colorectal cancer. (1)

Glossary (cont.)

Term	Definition (Source)
CAHPS	Consumer Assessment of Healthcare Providers and Systems
Cancer Stage	The extent of cancer in the body, including whether the disease has spread from the original site to other body sites. (1)
Chemotherapy	Treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing. Chemotherapy may be given by mouth, injection, or infusion, or on the skin, depending on the type and stage of the cancer being treated. It may be given alone or with other treatments, such as surgery, radiation therapy, or biologic therapy. (4)
Clinical Pathways	Clinical pathways—also referred to as “treatment pathways,” “patient pathways,” or simply “pathways”—are multidisciplinary plans of best clinical practices. In some respects, clinical pathways can be viewed as algorithms, outlining the sequence of treatment decisions to be made and the care to be provided for a given patient in a given condition. (5)
Clinical Practice Guidelines	Guidelines developed to help health care professionals and patients make decisions about screening, prevention, or treatment of a specific health condition. (4)
Complementary Therapies	Treatments that are used along with standard medical treatments but are not considered to be standard treatments. One example is using acupuncture to help lessen some side effects of cancer treatment (4)
Comprehensive Cancer Center	A cancer research center that gets support from the National Cancer Institute (NCI) to do cancer research and provide services directly to cancer patients. Scientists and doctors at these centers do basic laboratory research and clinical trials, and they study the patterns, causes, and control of cancer in groups of people. Also, they take part in multicenter clinical trials, which enroll patients from many parts of the country. Comprehensive Cancer Centers also give cancer information to health care professionals and the public. More information about the NCI Cancer Centers Program can be found on the NCI's Web site at http://cancercenters.cancer.gov . (4)

Glossary (cont.)

Term	Definition (Source)
Disparities	Health and health care disparities refer to differences in health and health care between groups. A “health disparity” refers to a higher burden of illness, injury, disability, or mortality experienced by one group relative to another. ¹ A “health care disparity” typically refers to differences between groups in health insurance coverage, access to and use of care, and quality of care. Health and health care disparities often refer to differences that are not explained by variations in health needs, patient preferences, or treatment recommendations and are closely linked with social, economic, and/or environmental disadvantage. The terms “health inequality” and “inequity” also are used to refer to disparities (6)
Dosimetrist	A medical dosimetrist is an analytical member of the radiation oncology team who works closely in collaboration with the radiation therapists, medical physicists, and radiation oncologists within the department. A medical dosimetrist has an overall knowledge of math, physics, anatomy & physiology, radiobiology, and knows the characteristics and clinical relevance of radiation oncology treatment machines and equipment. With their expertise, medical dosimetrists design, generate, and measure radiation dose distributions and dose calculations while providing oversight to high level treatment procedures in both external beam radiation therapy and brachytherapy. (7)
Genetic Counseling	A communication process between a specially trained health professional and a person concerned about the genetic risk of disease. The person's family and personal medical history may be discussed, and counseling may lead to genetic testing. (4)
Genetic Marker	A genetic marker is a DNA sequence with a known physical location on a chromosome. Genetic markers can help link an inherited disease with the responsible gene. (8)
Genomic testing	See “biomarker testing.”
Hospice	A program that gives special care to people who are near the end of life and have stopped treatment to cure or control their disease. Hospice offers physical, emotional, social, and spiritual support for patients and their families. The main goal of hospice care is to control pain and other symptoms of illness so patients can be as comfortable and alert as possible. It is usually given at home, but may also be given in a hospice center, hospital, or nursing home. (4)
Integrative Medicine	A type of medical care that combines conventional (standard) medical treatment with complementary and alternative (CAM) therapies that have been shown to be safe and to work. CAM therapies treat the mind, body, and spirit. (4)

Glossary (cont.)

Term	Definition (Source)
Mutation	A gene mutation is a permanent alteration in the DNA sequence that makes up a gene, such that the sequence differs from what is found in most people. (9)
National Cancer Institute	The National Cancer Institute, part of the National Institutes of Health of the United States Department of Health and Human Services, is the Federal Government's principal agency for cancer research. The National Cancer Institute conducts, coordinates, and funds cancer research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer. Access the National Cancer Institute Web site at http://www.cancer.gov . Also called NCI. (4)
NCCN	The National Comprehensive Cancer Network® (NCCN®), a not-for-profit alliance of 27 leading cancer centers devoted to patient care, research, and education. A listing of member institutions can be found at: https://www.nccn.org/members/network.aspx (10)
NCI	National Cancer Institute
NCI-designated centers	Cancer centers designated by the The National Cancer Institute (NCI), The NCI is part of the National Institutes of Health of the United States Department of Health and Human Services, is the Federal Government's principal agency for cancer research. The National Cancer Institute conducts, coordinates, and funds cancer research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer. Access the National Cancer Institute Web site at http://www.cancer.gov . Also called NCI. Source: https://www.cancer.gov/publications/dictionaries/cancer-terms/
NCQA	National Committee for Quality Assurance
NIH	National Institutes of Health

Glossary (cont.)

Term	Definition (Source)
Oncology PCMH	<p>NCQA has retired the Oncology Medical Home Recognition Program effective October 25, 2019. Practices that have already earned recognition will maintain their status through their expiration date. For a listing of the oncology practices that were pioneers of this program, visit the NCQA Report Cards.</p> <p>Practices that were planning on pursuing NCQA Oncology Medical Home Recognition should instead pursue Patient-Centered Specialty Practice (PCSP) Recognition. The PCSP Recognition program builds on Patient-Centered Medical Home (PCMH) Recognition program by recognizing specialty practices that excel in delivering high-quality, patient-centered care. It focuses on proactive coordination and sharing information where everyone in the practice works as a team to coordinate care with primary care, other referring clinicians, community resources and secondary services.</p> <p>The Oncology Medical Home Recognition program featured 7 standards area. The first 6 standards areas are the same standards that are a part of the PCSP Recognition Program. If you were preparing for Oncology Medical Home Recognition, you are already well-positioned to meet PCSP Recognition criteria. (11)</p>
Palliative Care	A medical specialty that focuses on symptom management and quality of life. (1)
Palliative Care	Treatment that relieves symptoms, such as pain, but is not expected to cure disease. Curative treatment can be used at the same time as palliative treatment, but the main purpose of palliative care is to improve the patient’s quality of life. (12)
Placebo	An inactive substance, sometimes called a “sugar pill.” Placebos are almost never used in cancer clinical trials. Most studies involve getting the standard of care for the specific cancer type. (1)
Precision Medicine	A process to find the best treatments for each specific patient based on exact gene changes or proteins in their cancer. Your doctors test for biomarkers, cell changes (mutations), or other targets found in/on your cancer cells. Then treatments are offered that target the specific biomarker or mutation found in your cancer. These “targeted” drugs are expected to work better. Sometimes called personalized medicine. (1)
QCP	Quality Oncology Practice Initiative (QOPI®) Certified Practice
QOPI	Quality Oncology Practice Initiative

Glossary (cont.)

Term	Definition (Source)
Radiation Therapy	The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy or brachytherapy). Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that travels in the blood to tissues throughout the body. Also called irradiation and radiotherapy. (4)
Shared Decision Making	In medicine, a process in which both the patient and healthcare professional work together to decide the best plan of care for the patient. When making a shared decision, the patient's values, goals, and concerns are considered. Shared decision making helps patients learn more about their health condition, the different testing and treatment options that may be available, and the possible risks and benefits of each option. It is often used when important medical decisions need to be made, such as about having a genetic test or cancer screening test, having major surgery, or taking a medicine over a long time. (4)
Survivorship	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. (4)
Survivorship Care Plan	A detailed plan given to a patient after treatment ends, that contains a summary of the patient's treatment, along with recommendations for follow-up care. In cancer, the plan is based on the type of cancer and the treatment the patient received. A survivorship care plan may include schedules for physical exams and medical tests to see if the cancer has come back or spread to other parts of the body. Getting follow-up care also helps check for health problems that may occur months or years after treatment ends, including other types of cancer. A survivorship care plan may also include information to help meet the emotional, social, legal, and financial needs of the patient. It may include referrals to specialists and recommendations for a healthy lifestyle, such as changes in diet and exercise and quitting smoking. Also called follow-up care plan. (4)

Glossary (cont.)

Term	Definition (Source)
Targeted therapy	Drugs that target specific cellular pathways that enable cancer cells to grow. (1)
Tumor Board Review	A treatment planning approach in which a number of doctors who are experts in different specialties (disciplines) review and discuss the medical condition and treatment options of a patient. In cancer treatment, a tumor board review may include that of a medical oncologist (who provides cancer treatment with drugs), a surgical oncologist (who provides cancer treatment with surgery), and a radiation oncologist (who provides cancer treatment with radiation). Also called multidisciplinary opinion. (4)
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United States Preventive Services Task Force (USPTF)	The U.S. Preventive Services Task Force is an independent, volunteer panel of national experts in disease prevention and evidence-based medicine. The Task Force works to improve the health of all Americans by making evidence-based recommendations about clinical preventive services. (13)
VA	Veterans Administration

Glossary (Sources)

- (1) Cancer Support Community
- (2) www.nhpco.org/patients-and-caregivers/advance-care-planning/
- (3) <https://www.asco.org/about-asco> [Module]
- (4) www.cancer.gov
- (5) www.journalofclinicalpathways.com/article/evolution-clinical-pathways-oncology
- (6) www.kff.org
- (7) www.medicaldosimetry.org/about/medical-dosimetrist/
- (8) www.genome.gov/glossary/index.cfm?id=86
- (9) www.ghr.nlm.nih.gov/primer/mutationsanddisorders/genemutation
- (10) www.nccn.org/about/default.aspx
www.ncqa.org/programs/health-care-providers-practices/oncology-medical-home/oncology-medical-home-recognition-program-retirement/
- (11) www.cancer.org/cancer/glossary.html (American Cancer Society)
- (12) www.uspreventiveservicestaskforce.org/

Additional Resources

Advance Care Planning

AARP

<https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/>

American Bar Association

https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning/

Cancer Support Community

<https://www.cancersupportcommunity.org/radio-show/spotlight-metastatic-breast-cancer-advanced-care-planning>

National Academy of Sciences. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life, 148-154 (2015)

National Hospice and Palliative Care Organization

<https://www.nhpco.org/>



Additional Resources

Survivorship Planning

American Society of Clinical Oncology

<https://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans>

OncoLink (University of Pennsylvania)

<https://oncolife.oncolink.org/>

