

**Citizen Scientist  
Cancer Research Curriculum:  
Instructor Guide**

## Table of Contents

Overview .....	4
Lesson Components.....	4
Implementation Timeframe.....	5
Completion of the course .....	6
Site Orientation.....	6
Contact.....	6
MODULE 1: Intro to Cancer and Cancer Research.....	7
1.1- What is Cancer? .....	7
1.2- Patient Case Study: Part 1.....	9
1.3- Citizen Scientists: Providing New Perspectives to Advance Cancer Research.....	9
1.4- Clinical Trials 101 .....	9
1.5- Spotlight on Citizen Scientists: Kristie.....	11
MODULE 2: Causes of Cancer .....	12
2.1- What is Cancer? .....	12
2.2- Patient Case Study: Part 2.....	14
2.3- Research Team Meeting: Renne Lab .....	14
2.4- Team Science .....	15
2.5- Spotlight on Citizen Scientists: Stan.....	15
MODULE 3: Treatment of Cancer .....	16
3.1- Surgical Treatment of Cancer .....	16
3.2- Patient Case Study: Part 3.....	18
3.3- Palliative Care .....	18
3.4- Breast Cancer Treatment: A Multidisciplinary Team Approach .....	20
3.5- Clinical Trial Enrollment .....	20
MODULE 4: Prevention and Survivorship .....	23
4.1- Cancer Prevention .....	23
4.2- Patient Case Study: Part 4.....	25
4.3- Survivorship .....	25
4.4- Patient Case Study: Part 5.....	25
4.5- Spotlight on Citizen Scientists: Shirley.....	26
4.6- Patient Case Study: Part 6.....	26

MODULE 5: Social Determinants of Health and Cancer .....	27
5.1- What are Social Determinants of Health? .....	27
5.2- Importance of Social Determinants of Health .....	29
5.3- Mapping Cancer Health Outcomes and Disparities.....	31
5.4- Social Determinants of Health in Clinical Practice.....	31
5.5- Spotlight on Citizen Scientists: Angela and Nadine .....	31
Final Note.....	32

## Overview

Thank you for your interest in the University of Florida Citizen Scientist Cancer Research Curriculum. This instructor guide was created to help facilitate self-paced learning in the online modules with classroom-based learning through guided discussions. The curriculum can be implemented using multiple formats, including online, classroom, or blended learning techniques. This guide presents lesson contents including learning objectives and pre-lesson thought questions that were written to help learners better conceptualize the didactic content. Those structured elements have been paired here with additional components to help illustrate didactic concepts in a way that learners can relate to and understand. The prescribed sequence of the curriculum is merely a suggestion; the final order of the contents and the navigation plan is entirely up to instructors. Level of mastery required for each lesson is also at the discretion of the instructor: whether or not participants need a minimum score to proceed, whether they can retake a module, etc. can differ by site or group based on the needs of the learners.

### Lesson Components

The additional lesson components included in this guide are:

- **Assessment Questions-** Each didactic video is paired with five assessment questions to gauge knowledge retention and comprehension of the lesson topic. Instructors can either have participants work through this course online (whether on the public website or in a learning management system like Canvas) or during group sessions, the group can watch the videos and answer the questions. Whether the participants answer questions out loud together, or on paper individually is a decision for the group instructor.
- **Reflection Questions-** These questions accompany each didactic lesson and will help participants reflect on the topic and organize their thoughts accordingly. These questions can also be used to facilitate group discussions, though this may depend on the level of comfort of group participants. Instructors should review the questions and be prepared to address participant responses to these questions. If using as group discussion questions, be sure to establish ground rules for sharing responses: some of these topics may evoke strong emotions in learners, and the group should be respectful of the experiences of others. Additional questions can be added or substituted as needed. These discussion questions could easily be utilized as forum or discussion postings in an online learning management system if in-person meetings are not feasible.
- **Additional Resources-** extra resources, in addition to those listed in the online lesson contents, that can help participants better understand the lesson topic. Accessing these items can be voluntary or required, as desired by the instructor. These resources can be assigned as additional reading either during completion of the lesson, or after the lesson is discussed as a group.

These components are intended to promote discussion among participants following completion of the lesson(s); for example, the reflection questions listed in lesson 1.1 should only be implemented once

participants have completed the lesson and assessment. Depending on the amount of time elapsed between when participants complete the lesson on their own and an in-person group discussion, it may be helpful to replay the video to remind participants of specific points mentioned in the video that may be applicable to the suggested questions and or supplemental resources.

All activities, resources, and discussion questions presented in this guide are complimentary elements intended to enhance the curriculum content, and can be enhanced, revised, or omitted if they do not fit the vision of the program. As is the case with the curriculum contents, this guide is an open educational resource (OER) and can be edited to fit the needs of individual sites.

### Implementation Timeframe

The suggested approach for presenting this information is to have participants work through each module or lesson on their own and then meet up (either virtually or in-person) as a group to discuss the new concepts. Lesson assignments and discussions can be divided as the instructor deems necessary. Suggested timeframes for completing the online lessons and holding group discussions are shown in Tables 1 and 2. In these examples, the group meets on Fridays, and each meeting’s discussion focuses on the lesson(s) they completed earlier in the week. At the conclusion of each group meeting, the next lesson(s) is assigned to be completed prior to the following week’s meeting.

It is suggested that instructors bear in mind how many didactic lessons are being assigned at one time: These topics can be overwhelming for beginners, and it may be best to space out didactic assignments so that only one is completed per week. The didactic lesson assignment can be supplemented with other lessons that are not as overwhelming. An example of this approach appears in Table 1.

Table 1: Timeframe example for long-term implementation (didactic lessons in bold):

Date	Lessons Completed at Home	Group Discussions (every Friday)	Homework Assigned at Group Discussion
Week 1 (Fri- Thurs)	Lessons <b>1.1</b> , 1.2	Lessons <b>1.1</b> , 1.2	Lessons 1.3, <b>1.4</b> , 1.5
Week 2 (Fri- Thurs)	Lessons 1.3, <b>1.4</b> , 1.5	Lessons 1.3, <b>1.4</b> , 1.5	Lessons <b>2.1</b> , 2.2
Week 3 (Fri- Thurs)	Lesson <b>2.1</b> , 2.2	Lesson <b>2.1</b> , 2.2	Lessons 2.3, 2.4, 2.5
Week 4 (Fri- Thurs)	Lessons 2.3, 2.4, 2.5	Lessons 2.3, 2.4, 2.5	Lessons <b>3.1</b> , 3.2
Week 5 (Fri- Thurs)	Lessons <b>3.1</b> , 3.2	Lessons <b>3.1</b> , 3.2	Lesson <b>3.3</b>
Week 6 (Fri- Thurs)	Lesson <b>3.3</b>	Lesson <b>3.3</b>	Lessons 3.4, <b>3.5</b>
Week 7 (Fri- Thurs)	Lessons 3.4, <b>3.5</b>	Lessons 3.4, <b>3.5</b>	Lessons <b>4.1</b> , 4.2, 4.3
Week 8 (Fri- Thurs)	Lessons <b>4.1</b> , 4.2, 4.3	Lessons <b>4.1</b> , 4.2, 4.3	Lessons 4.4, 4.5, 4.6
Week 9 (Fri- Thurs)	Lessons 4.4, 4.5, 4.6	Lessons 4.4, 4.5, 4.6	Lesson <b>5.1</b>
Week 10 (Fri- Thurs)	Lesson <b>5.1</b>	Lesson <b>5.1</b>	Lessons <b>5.2</b> , 5.3
Week 11 (Fri- Thurs)	Lessons <b>5.2</b> , 5.3	Lessons <b>5.2</b> , 5.3	Lessons 5.4, 5.5
Week 12 (Fri- Thurs)	Lessons 5.4, 5.5	Lessons 5.4, 5.5	

However, it may not always be possible to space out the implementation of this content, due to time or

funding constraints. In this situation, participants can move through a module per week, as outlined in Table 2.

Table 2: Timeframe example for short-term implementation:

Date	Lessons Completed at Home	Group Discussions (every Friday)	Homework Assigned at Group Discussion
Week 1 (Fri- Thurs)	Module 1	Module 1	Module 2
Week 2 (Fri- Thurs)	Module 2	Module 2	Module 3
Week 3 (Fri- Thurs)	Module 3	Module 3	Module 4
Week 4 (Fri- Thurs)	Module 4	Module 4	Module 5
Week 5 (Fri- Thurs)	Module 5	Module 5	

### Completion of the course

Unlike the prior Citizen Scientist curriculum that laid groundwork for basic research concepts, this course does not utilize a certification program. It is the suggestion of the curriculum team to create a meaningful way to acknowledge successful completion of the course, as this is a more nuanced training beyond basic research knowledge and would offer participants a way to discuss and market this skill. For example, awarding participants a certificate or trophy with the designation of “Citizen Scientist: Cancer Research Certification” is one way to formally acknowledge completion of this course, though individual details are at the discretion of each site and may depend on terminology and funding.

### Site Orientation

As cancer centers can be complex organizations and researchers may serve dual roles across the larger institution, we suggest starting the course implementation with an overview to your site’s structure. This can include a breakdown of the different departments, teams, or divisions within the cancer center, as well as background on the different leaders and their oversight areas. We also suggest discussing the notion that researchers may serve in dual appointments; that is, a researcher who works with Citizen Scientists may be housed within the department of pathology through the medical school, but may be a crucial part of the cancer center’s research through their affiliations or grants. This site-specific overview may help offer context for Citizen Scientists prior to engaging in research work through your home institution.

### Contact

Please contact our team with any questions or feedback you have:

The University of Florida Citizen Scientist Curriculum Team

[OneFloridaOperations@health.ufl.edu](mailto:OneFloridaOperations@health.ufl.edu)

## MODULE 1: Intro to Cancer and Cancer Research

### 1.1- What is Cancer?

This video provided a basic definition of cancer, cancer terminology, and the characteristics and processes related to cancer development.

#### Pre-Lesson Thought Questions

- What is cancer?
- What are the main signs of cancer?
- Is cancer a single disease?

#### Lesson Learning Objectives

- Name the causes of cancer
- Describe how cancer forms
- Cite different terms used for cancer

Video run time: 7:22

Assessment Questions (Note that correct responses are bolded)

1. Which of the following definitions best describes cancer?
  - A. Cancer is the term used to describe a small number of related diseases.
  - B. Cancer is a disease characterized by controlled division of cells.
  - C. Cancer is a disease characterized by uncontrolled division of cells.**
  - D. Cancer is a disease caused by red blood cells.
2. Which of the following terms can be used for cancer?
  - A. Tissue, Organs, and Systems
  - B. Neolithic, Edema, Systems
  - C. Inflammation, Toxins, Cerebrovascular diseases
  - D. Malignancy, Neoplasm, and Tumor**
3. Which of the following is correct about Tumorigenesis?
  - A. Tumorigenesis describes the process of how cancer arises.**
  - B. Tumorigenesis describes a specific cancer.
  - C. Tumorigenesis describes the process of how cancer is treated.
  - D. Tumorigenesis describes healthy cell growth.
4. Read the following scenario and then select the best answer for the question:

Olivia is a 45-year-old woman who was recently diagnosed with breast cancer. When the oncologist mentioned that there are different types of breast cancer, she was visibly surprised. Based on this information, what should Olivia expect in her treatment?

- A. There will be only one approach to treat her cancer.
- B. There will be no treatments for her specific cancer.
- C. Her treatment will be tailored to her specific situation.**
- D. Her overall lifestyle and health condition will not be considered in her treatment plan.

Olivia's treatment plan will be tailored to her specific situation in terms of cancer characteristics as well as her overall health condition.

5. Read the following scenario and then select the best answer for the question:  
After looking for clinical treatment for a variety of conditions such as cough, pain in the chest, and shortness of breath, Richard, a 65-year-old, was diagnosed with lung cancer and was told that the tumor cells have migrated to other parts of his body. Which of the following is true about Richard's lung cancer?
- A. There is unregulated cell growth in his lungs
  - B. The cancer has spread to other areas of his body
  - C. There is limitless cell growth in his lungs
  - D. All of the above**

#### Reflection Questions

We suggest giving learners 10 minutes or so to consider these questions and reflect on them. These questions can also be used as a way to facilitate a group discussion about this content.

- Is the topic of cancer new to you?
- Did anything in the video stand out to you?
- How did it make you feel?

#### Additional Resources

##### [What is Cancer?](#)

This National Cancer Institute (NCI) site offers additional details about different types of cancers and how cancer spreads.

##### [NCI Dictionary of Cancer Terms](#)

Also from the NCI, this site contains a large number of cancer-related abbreviations and terms that may be helpful for Citizen Scientists working to understand the terminology of this field.



## **1.2- Patient Case Study: Part 1**

Presented over several modules, this case study follows a patient, parents, and physician through the course of cancer diagnosis, treatment, and survivorship. In Part 1, you heard from the patient perspective, including the difficulty in obtaining an accurate diagnosis.

Lesson Learning Objectives

- List some of the alternative diagnoses the patient received prior to the final diagnosis
- Discuss why the patient wasn't worried about enrolling in a clinical trial

## **1.3- Citizen Scientists: Providing New Perspectives to Advance Cancer Research**

This animated video offered an overview of the causes and the toll of cancer, and discussed how Citizen Scientists can have a unique impact on research done on this critical topic.

Lesson Learning Objectives

- Explain why cancer causes cells to stop acting normally
- Describe how Citizen Scientists can support a patient-centered approach to cancer research

*Video Coming Soon!*

## **1.4- Clinical Trials 101**

This lesson described the intents, phases, and the criteria for clinical trial selection by research institutions.

Pre-Lesson Thought Questions

- What is the intent of clinical trials?
- How do research institutions decide which clinical trials will open?
- What are the main characteristics of the different phases of clinical trials?

Lesson Learning Objectives

- Identify the different phases of clinical trials
- Discuss how clinical trials can be used to evaluate the safety and efficacy of different types of interventions (e.g., drugs, exercise)
- Describe the criteria used by research centers in selecting which clinical trials should be offered

Video run time: 6:31

Assessment Questions (Note that correct responses are bolded)

1. Which of the following is true about clinical trials?
  - A. They are only intended to evaluate medications.
  - B. They are intended to evaluate health insurance costs for patients with cancer.
  - C. They are intended to evaluate new medical facilities that care for patients with cancer.
  - D. **They are intended to evaluate treatment, diagnostic, prevention, screening, or supportive care.**
  
2. Which of the following questions could be addressed in a clinical trial focusing on the prevention of cancer?
  - A. Do daily exercises decrease the incidence of lung cancer among women over 40?
  - B. Does a routine multivitamin decrease the risk of prostate cancer?
  - C. Is a new HPV vaccine more effective in preventing head and neck cancer than a commercialized version of the vaccine?
  - D. **All of the above**
  
3. Can clinical trials be used to evaluate the quality of life of patients undergoing cancer treatments?
  - A. Yes. In these cases, clinical trials are mandatory to improve the well-being of patients as they undergo treatment.
  - B. **Yes. One example would be the evaluation of whether participation in yoga or support groups can improve the well-being of patients as they undergo treatment.**
  - C. No. Clinical trials are only intended to evaluate cancer treatments and prevention.
  - D. No. Clinical trials are only intended to test new drugs and procedures.
  
4. Read the following scenario and then select the best answer for the question:  
Talisha's family has a history of ovarian cancer and now, at age 65, Talisha knows about her increased risk of developing ovarian cancer. Based on her risk factors, Talisha enrolled in a clinical trial that aims at improving the early detection of cancer cells in the ovaries. The innovative procedure involves the use of a drug that has only been tested in small animal models (e.g., mice). Which of the following phases best represents the clinical trial in which Talisha has enrolled?
  - A. **Phase 0: involves first trials done with humans.**
  - B. Phase II: evaluates the efficacy of treatment.
  - C. Phase III: compares treatments targeting those with fewest side effects.
  - D. Phase IV: evaluates long-term side effects.

The clinical trial in which Talisha has enrolled represents a phase 0 clinical trial because it is the first time the drug will be tested in humans. In phase 0 trials, researchers want

to see how a small dose of the medication is processed in the body and how it affects the body. This type of study is rare and usually only done by pharmaceutical companies.

5. Read the following scenario and then select the best answer for the question:  
Researchers in the center where Talisha is a patient and study participant followed standardized procedures to begin the clinical trial. These procedures include the consideration of important criteria and the approval by the institutional review board (IRB). Which of the following criteria are often used by research centers to decide which clinical trials will be offered to patients?
- A. **Clinical trials are selected on the basis of patient needs, best available science, and greatest impact.**
  - B. Clinical trials are selected on the basis of institutions' administrative demands.
  - C. Clinical trials are selected on the basis of benefits to pharmaceutical companies or other sponsors developing the intervention.
  - D. As long as a clinical trial has funding available, it will be offered.

#### Reflection Questions

We suggest giving learners 10 minutes or so to consider these questions and reflect on them. These questions can also be used as a way to facilitate a group discussion about this content.

- Is the topic of clinical trials new to you?
- Did anything in the video stand out to you?
- How did it make you feel?

#### Additional Resources

##### [What Are Clinical Trials?](#)

From the National Cancer Institute, this site offers introductory information about clinical trials, including what information is typically included in the research protocol.

##### [Types and Phases of Clinical Trials](#)

This site details information about how different types of trials are helpful and what is included in each phase.

#### **1.5- Spotlight on Citizen Scientists: Kristie**

This video describes the work done by a Citizen Scientist on cancer research, as well as how personal experiences can help shape research.

Video run time: 7:32

## MODULE 2: Causes of Cancer

### 2.1- What is Cancer?

This lesson provides an overview of the environmental and genetic factors that can cause cancer. Some questions to consider while completing this lesson include:

- What causes cancer?
- What are examples of external causes of cancer?
- How was the linkage between chemicals and cancer proven?

#### Lesson Learning Objectives

- Explain what factors can cause cancer
- Describe how workplace chemicals played a role in our understanding of cancer and its causes
- Cite the three main environmental factors that can lead to cancer development

Video run time: 7:28

#### Assessment Questions (Note that correct responses are bolded)

1. What are the three major external causes of cancer?
  - A. Chemicals, metaphase, genetics
  - B. Chemicals, meiosis, radiation
  - C. Chemicals, mitosis, genetics
  - D. Chemicals, microorganisms, radiation**
2. Which of the following is a well-known cancer-related microorganism?
  - A. Staphylococcus epidermidis
  - B. Agaricus bisporus
  - C. Human papillomavirus**
  - D. Entamoeba coli

The human papillomavirus (HPV) is known to cause six types of cancers including cervical cancer and head and neck cancers.

3. How can we describe Dr. Yamagiwa's discovery of the linkage between chemicals and cancer?
  - A. It was based on observations only. He noticed that some rabbits in the wild had coal tar in their ears and, later, these rabbits developed cancer.

- B. It was based on an experiment. Coal tar was painted on rabbits' ears which lead to cancer.**
- C. He proposed the connection between coal tar and cancer from his study of zoology and history books.
- D. It was based on his intuition and notes from his entire career as a pathologist.
4. Read the following scenario and then select the best answer for the question:  
Charlotte loves going to the beach in sunny Florida. When she cannot go to the beach, she uses tanning beds. However, more recently, Charlotte has been concerned about her frequent exposure to UV rays because her brother has been diagnosed with skin cancer.  
Which of the following reasons could explain Charlotte's concerns?
- A. Sun exposure is a well-known environmental factor associated with cancer.
- B. There is a chance that Charlotte and her brother have an inherited genetic predisposition for skin cancer.
- C. Tanning beds also emit UV rays that cause skin damage and can lead to cancer.
- D. All of the above.**
5. Read the following scenario and then select the best answer for the question:  
Rick is a Melanoma cancer survivor. He is also a father of three young children. Rick believes that prevention is key to keep his children safe and healthy. In addition to a nutritious diet and active lifestyle, which of the following measures can Rick take to help protect his children from developing cancer?
- A. The only thing Rick can do is to have his children vaccinated against HPV.
- B. Rick's actions cannot reduce the risks of cancer development in his children.
- C. The only thing Rick can do is to have his children use sunscreen.
- D. Rick can have his children use sunscreen and get recommended vaccines such as HPV and hepatitis B and C vaccines.

#### Reflection Questions

We suggest giving learners 10 minutes or so to consider these questions and reflect on them. These questions can also be used as a way to facilitate a group discussion about this content.

- Is the topic of causes of cancer new to you?
- Did anything in the video stand out to you?
- How did it make you feel?

#### Additional Resources

##### [Common Cancer Types](#)

From the National Cancer Institute (NCI), this page offers a look at the most common types of cancers in the United States, as well as the estimated number of new cases and deaths per year. Each type of

cancer links to a separate page that gives more information specific to that cancer, including causes, treatment, and screening information.

## **2.2- Patient Case Study: Part 2**

Presented over several modules, this case study follows a patient, parents, and physician through the course of cancer diagnosis, treatment, and survivorship. In Part 2, you will hear from the caregiver perspective, including insight on navigating a cancer diagnosis and treatment as well as how Citizen Scientists can help impact patient care.

### Lesson Learning Objectives

- Describe the social impact cancer can have on older children and teenagers
- Discuss the importance of a positive outlook in patients and families battling cancer

Video run time: 7:52

## **2.3- Research Team Meeting: Renne Lab**

In order to know what a Citizen Scientist may need to contribute to a research meeting, it is helpful to understand the nature of the content discussed, and the dynamics of, team research meetings. In this series, you will first watch an introduction to help lay the groundwork for the meeting. Then, you will see a behind-the-scenes view of a research meeting during which data, decision making, and progress to date are reviewed by the team.

### Lesson Learning Objectives

- Explain how research meetings foster collaboration
- Propose how Citizen Scientists can potentially contribute to similar meetings

Note: For these types of research meetings, a Citizen Scientist would typically have prior knowledge of the topic or disease. As this meeting skips that step, some background information about the disease discussed in the video is below. This information will provide context as you watch the video:

- Kaposi's Sarcoma (KS) is a type of cancer triggered by immunodeficiency in those with the Kaposi's sarcoma-associated herpesvirus (KSHV).
- Because all KS tumors are caused by KSHV, there is no healthy "control" sample of a tumor without the virus to compare to, and it will be tough to figure out which treatments may have an impact.
- KSHV can be dormant, or latent, in the body for a long time while prompting cell growth that will lead to cancer.

Video 1 (Intro) run time: 1:20

Video 2 (Lab Meeting) run time: 10:24

## **2.4- Team Science**

This video describes the importance of each member of the research team and how knowledge gaps are filled by relying on the expertise brought by team members.

### Lesson Learning Objectives

- Describe how community perspective helped shape the research project described in the video
- State the importance of a statistician on a research team

Video run time: 3:25

## **2.5- Spotlight on Citizen Scientists: Stan**

This video describes the motivation of a Citizen Scientist to become involved with cancer research, as well as how personal experiences can help shape research.

Video run time: 7:49

## MODULE 3: Treatment of Cancer

### 3.1- Surgical Treatment of Cancer

This lesson contains an overview of the role of surgery in the diagnosis, evaluation, and treatment of cancer. Some questions to consider while completing this lesson include:

- How are surgical procedures used in the diagnosis and treatment of cancer?
- What is *en bloc* resection?
- What is a patient-centered multidisciplinary approach?

#### Lesson Learning Objectives

- Describe how types of biopsies differ
- Explain the advantages of a needle biopsy
- Discuss the role of a multidisciplinary treatment team

Video run time: 11:00

#### Assessment Questions (Note that correct responses are bolded)

1. Which of the following are true about all biopsies?
  - A. Biopsies should only be done during surgery so that the tumor and surrounding structures can be easily viewed.
  - B. Biopsies can be done with a needle and imaging or with open surgery.**
  - C. Biopsies should only be done if a cancer has spread to other parts of the body.
  - D. Biopsies should be done with caution, as they can cause the cancer to spread to the brain.

Biopsies can be done with imaging-guided needles or with open surgery depending on the type, size, and location of the cancer.
2. Which of the following is considered the gold standard when it comes to breast biopsy?
  - A. Needle biopsy**
  - B. Open surgical biopsy
  - C. Multilevel biopsy
  - D. Specialized surgical biopsy
3. What is true about *en bloc* tumor resection?
  - A. Involves the partial removal of a tumor and the lymph nodes that failed to block the cancer from spreading



- B. Involves the careful observation of a tumor over time
- C. Involves the removal of the entire tumor plus some normal tissue**
- D. Involves blocking a tumor from surrounding tissue

*En bloc* resection involves the removal of the entire tumor along with an edge of normal tissue in an effort to ensure that the cancer is truly removed.

4. Read the following scenario and then select the best answer for the question:  
Sabrina was diagnosed with stage II breast cancer. After considering her medical history and overall health condition, her doctors offered her two possible treatments: mastectomy with radiation or lumpectomy with radiation. How can her doctors use the information from clinical trials to help determine her best treatment option?
- A. They can have Sabrina follow the same treatments as all treatment groups (placebo and intervention) so that she will definitely get the best option at some point.
  - B. They can ask patients who enrolled in breast cancer clinical trials what they feel Sabrina's best option is based on their lived experiences.
  - C. They can send Sabrina the results of all breast cancer clinical trials and allow her to customize her treatment option based on the data.
  - D. They can review results of trials for patients who had similar types and staging of breast cancer to see which options led to better outcomes.**
5. Read the following scenario and then select the best answer for the question:  
Sophia is a resident physician in the oncology unit of a large university hospital. She is receiving training to be a surgical oncologist. As part of her training, she was given a patient case to evaluate. The patient is a 55-year-old man with a colon cancer diagnosis. The patient is a truck driver and takes care of his elderly parents who live with him. Considering that the oncology unit follows a multidisciplinary, patient-centered approach, what will Sophia do as part of her evaluation?
- A. She will only look at the patient's medical records and write a final report.
  - B. She will talk only to the surgical oncologist who has followed the patient and has an accurate idea about the patient's prognosis.
  - C. She will talk only with the social worker to understand how the treatment can be managed based on the patient's family situation.
  - D. She will read the patient's medical records and talk with members of the entire treatment team (surgeons, nurse, psychologist, etc.) who have followed the patient.**

Adhering to a multidisciplinary approach, Sophia will read the patient's medical records and will talk to the entire treatment team to conduct an evaluation that takes into consideration the patient's clinical situation as well as his physical and psychological well-being.

## Reflection Questions

We suggest giving learners 10 minutes or so to consider these questions and reflect on them. These questions can also be used as a way to facilitate a group discussion about this content.

- Is the topic of the role of surgery in the diagnosis and treatment of cancer new to you?
- Did anything in the video stand out to you?
- How did it make you feel?

### 3.2- Patient Case Study: Part 3

Presented over several modules, this case study follows a patient, parents, and physician through the course of cancer diagnosis, treatment, and survivorship. In Part 3, you will hear from the physician perspective, including the considerations that impacted the patient's treatment.

#### Lesson Learning Objectives

- Articulate some of the treatment options that were used with the patient
- Discuss why it can be challenging to treat cancers that cross the blood-brain barrier

Video run time: 7:30

#### Additional Resources

- [Philadelphia Chromosome](#)  
This explanation from the National Cancer Institute will help describe one of the topics in this video.
- [Bone Marrow Transplantation](#)  
This information from Johns Hopkins Medicine provides additional details about how bone marrow transplants are used to treat diseases like leukemia, as discussed in this video.

### 3.3- Palliative Care

Topics covered in this lesson include an overview about palliative care, possible misconceptions, and what palliative care means in the context of cancer patients. Some questions to consider while completing this lesson include:

- What is palliative care?
- Why is palliative care important for cancer patients?
- Is palliative care intended for specific age groups?

#### Lesson Learning Objectives

- Explain why palliative care is a key component in cancer treatments

- Provide examples of palliative care for cancer patients
- Discuss the relationship between palliative care and hospice care

Video run time: 6:18

Assessment Questions (Note that correct responses are bolded)

1. Which of the following is true about palliative care for cancer patients?

- A. It is only used for patients who are moving towards the end of their lives.
- B. It reduces quality of life among cancer patients.
- C. It can be used as part of the treatment for cancer.**
- D. It can be used to cure cancer.

Palliative care for cancer patients is often used as part of the treatment for cancer to manage pain, optimize comfort, and improve quality of life.

2. Which of the following is an example of palliative care for cancer patients?

- A. Blood transfusion to treat shortness of breath for patients with leukemia**
- B. Gene therapy to cure rare types of cancer
- C. HPV vaccine to prevent cancer
- D. Stem cell transplants to cure leukemia

3. How is palliative care for cancer patients determined?

- A. It is based on a case-by-case situation according to the needs and treatment history of the patient.
- B. The physician takes into consideration the pros and cons of a given treatment before prescribing it to the patient.
- C. The patient's input is considered in determining the best palliative care option.
- D. All of the above.**

4. Read the following scenario and then select the best answer for the question:

Bryan is a four-year old boy who was recently diagnosed with an aggressive type of brain cancer. Is palliative care an option for him?

- A. No, palliative care is only intended for adult patients.
- B. Yes, palliative care will likely improve his quality of life during the treatment of the disease.**
- C. No, palliative care will likely increase his pain and discomfort during the treatment of the disease.
- D. Yes, only children can benefit from palliative care.

5. Read the following scenario and then select the best answer for the question:  
Laura is a 40-year-old woman and has been diagnosed with an advanced-stage stomach cancer. Given Laura's need for 24-hour pain management care, she and her family made a difficult decision to use the services of a hospice care facility. What is true about hospice care?
- A. Hospice care is required prior to enrollments in clinical trials.
  - B. Hospice care will likely increase Laura's discomfort as pain medications are not allowed in these facilities.
  - C. Hospice care will allow Laura to receive innovative treatment to cure her stomach cancer.
  - D. Hospice care is entirely palliative care and will allow Laura to receive pain medication as needed to improve her quality of life.**

#### Reflection Questions

We suggest giving learners 10 minutes or so to consider these questions and reflect on them. These questions can also be used as a way to facilitate a group discussion about this content.

- Is the topic of palliative care new to you?
- Did anything in the video stand out to you?
- How did it make you feel?

### **3.4- Breast Cancer Treatment: A Multidisciplinary Team Approach**

This video describes how different types of providers come together to provide a patient-centered treatment plan for cancer patients. This video includes a patient case study to help illustrate this concept.

#### Lesson Learning Objectives

- List members of a multidisciplinary care team for breast cancer
- Describe the outcome and prognosis for the case study patient, Ms. Y

Video run time: 9:42

### **3.5- Clinical Trial Enrollment**

In this lesson you will learn how institutions, healthcare providers, and patient characteristics can impact enrollment and representation in clinical trials. This lesson also covers how Citizen Scientists can play a crucial role in this research process. Some questions to consider while completing this lesson include:

- What are the main categories of barriers to clinical trial enrollment?
- How can health care providers impact the outcomes in clinical trial enrollment?
- How can Citizen Scientists influence the outcomes in clinical trial enrollment?

## Lesson Learning Objectives

- Identify the main institutional barriers to clinical trial enrollment
- Discuss how provider barriers can impact representation in clinical trial enrollment
- Provide examples of patient barriers to clinical trial enrollment

Video run time: 7:05

## Assessment Questions (Note that correct responses are bolded)

1. Which of the following are examples of institutional barriers to clinical trial enrollment?
  - A. Restrictive costs, provider lack of communication skills, overtrained staff
  - B. Unlimited availability of trials, patient lack of interest, patient low awareness
  - C. Lack of sufficient/trained research staff, restrictive criteria for enrollment, limited availability of trials**
  - D. Focus on patient representation, provider bias, patient lack of interest
2. Which of the following is an example of provider bias?
  - A. The provider discusses available clinical trials with all his/her patients.
  - B. The provider is not aware of clinical trials available to address a patient's condition.
  - C. The provider does not know how to effectively communicate with patients about available clinical trials.
  - D. The provider inappropriately judges patient eligibility based on factors such as ethnicity or socioeconomic status.**

All patients should be made aware of the clinical trials available to them, regardless of whether or not the provider thinks the patient is interested. Providers may make assumptions about a patient's interest based on what they see or what they think: A patient will need to give their consent prior to enrolling in a trial, and someone more knowledgeable about that trial will take the time to explain all of the risks and benefits prior to enrollment so that the patient can make the decision for themselves. Whether or not the patient is even interested in a trial should not be left up to the provider.

3. How does patient level of awareness influence clinical trial enrollment?
  - A. Patients who are not aware of available clinical trials will not seek to enroll in them.**
  - B. Patients who are aware of clinical trials are more likely to understand the funding and approval processes related to clinical trials, making them ineligible to enroll.
  - C. Lack of awareness creates an insignificant barrier to enrollment in clinical trials.
  - D. Patients who are not aware of clinical trials will be more likely to enroll in them.
4. Read the following scenario and then select the best answer for the question:

Dr. Williams is the director of the cancer center in a large research institution. One of her primary responsibilities is to improve clinical trial enrollment in the center. Which of the following initiatives could be used by Dr. Williams to facilitate clinical trial enrollment?

- A. Establish programs to support work-life balance initiatives for researchers and other staff members in the center.
  - B. Create programs to train primary care providers to have better conversations with patients about available clinical trials.**
  - C. Create policies that prevent primary care providers from discussing available clinical trials with their patients.
  - D. Search for financial incentives to support the commercialization of new therapeutic approaches.
5. Read the following scenario and then select the best answer for the question:  
Charles is a Citizen Scientist involved in developing a new cancer clinical trial. He has worked on other research projects before and understands how his input can help improve research processes such as patient recruitment. What are some important **patient barriers** to clinical trial enrollment that Charles will likely discuss with other members of the research team during their group meetings?
- A. The risk of provider bias and poor communication skills.
  - B. The restrictive eligibility criteria considered by the research institution.
  - C. Limited availability of clinical trials and lack of trained staff in the institution.
  - D. Transportation to and from clinical trial sites and other logistical challenges.**

#### Reflection Questions

We suggest giving learners 10 minutes or so to consider these questions and reflect on them. These questions can also be used as a way to facilitate a group discussion about this content.

- Is the topic of clinical trial enrollment new to you?
- Did anything in the video stand out to you?
- How did it make you feel?

#### Additional Resources

##### [The Need for Clinical Trial Navigators](#)

This piece, written by a cancer survivor who participated in a clinical trial, details how use of clinical trial navigators can help increase knowledge about, and participation in, clinical trials.

Note that this content may be behind a paywall. If this is the case, check to see if your institution has a use agreement with NYT to grant access.

## MODULE 4: Prevention and Survivorship

### 4.1- Cancer Prevention

This lesson addresses how behaviors and choices can increase or reduce risk factors for cancer. Some questions to consider while completing this lesson include:

- What are the risk factors for cancer?
- Can we control all of the risk factors related to cancer?
- What can we do to help to prevent cancer?

#### Lesson Learning Objectives

- Provide examples of risk factors for cancer
- Explain how some behaviors can help to prevent cancer
- Discuss the role of early screening in the prevention of cancer

Video run time: 4:48

Assessment Questions (Note that correct responses are bolded)

1. What are the risk factors for cancer that are usually out of our control?
  - A. Genetics and food choice
  - B. Genetics and environment**
  - C. Food choice and lifestyle
  - D. All risk factors can be controlled
2. Which of the following is true about cancer prevention?
  - A. About 7% of our lifetime risk is within our ability to change.
  - B. About 17% of our lifetime risk is within our ability to change.
  - C. About 70% of our lifetime risk is within our ability to change.
  - D. About 99% of our lifetime risk is within our ability to change.
3. What types of cancer can usually be prevented by avoiding tobacco use?
  - A. Only lung and pancreas cancers
  - B. Lung, head and neck, pancreas, bladder, cervix, and kidney cancers**
  - C. Brain and breast cancers
  - D. Liver and prostate cancers
4. Read the following scenario and then select the best answer for the question:  
Adam's family is fond of processed foods such as pepperoni and potato chips. They barely consume fruits and vegetables. Recently, Adam's father was diagnosed with kidney cancer. To reduce his own chances of developing kidney or other types of cancer

associated with a poor diet such as breast, colon, lung, and liver cancer, Adam is trying to change his diet. Which of the following would help Adam reduce the risk of developing cancer?

- A. Buying a wider variety of processed food.
- B. Using new recipes to prepare his favorite processed foods.
- C. Avoiding processed food and consuming more fruits and vegetables.**
- D. Increasing the consumption of processed food.

5. Read the following scenario and then select the best answer for the question: To create public awareness of cancer prevention, a cancer center created a brochure that highlights how people should avoid risky behaviors such as unsafe sex and sharing of needles to reduce their risk of developing cancer associated with HPV, HIV, and Hepatitis B or C viruses. The brochure also emphasizes the value of early screening, especially for cancer survivors. Should cancer survivors be mentioned in a brochure addressing cancer prevention?

- A. Yes, healthy lifestyle and early screening are helpful to prevent or identify any type of secondary cancer.**
- B. Yes, but only for some types of survivors such as head and neck cancer survivors.
- C. No, people who have had cancer will not benefit from a healthy lifestyle or early screening.
- D. No, if cancer survivors have been declared cancer free they cannot develop cancer again.

Cancer survivors should be mentioned in the brochure because healthy lifestyle and early screening are helpful to prevent or identify any type of cancer, even in those who have already had cancer.

#### Reflection Questions

We suggest giving learners 10 minutes or so to consider these questions and reflect on them. These questions can also be used as a way to facilitate a group discussion about this content.

- Is the topic of cancer prevention new to you?
- Did anything in the video stand out to you?
- How did it make you feel?

#### Additional Resources

##### [Risk Factors and Cancer](#)

From the Centers for Disease Control and Prevention, this site offers a more in-depth look into the different cancer risk factors a person can have- both genetic and not.



#### **4.2- Patient Case Study: Part 4**

Presented over several modules, this case study follows a patient, parents, and physician through the course of cancer diagnosis, treatment, and survivorship. In Part 4, you will hear from the patient perspective, including what survivorship means to the patient.

##### Lesson Learning Objectives

- Articulate how the patient and family used social media to help others
- Explain what it means to this patient to be a survivor

Video run time: 6:18

#### **4.3- Survivorship**

This video discusses how clinicians help care for cancer patients after the treatment is over.

##### Lesson Learning Objectives

- Identify some of the side effects caused by cancer treatments
- List some of the components of a survivorship care plan

Video run time: 3:08

##### Additional Resources

##### [Scar Stories: The Toll of Colon Cancer](#)

Colon cancer is a lesser-known type of cancer, and one that disproportionately affects minorities. This photojournalism piece, published in the May 2021 issue of GQ magazine, explores the perspectives of male colon cancer survivors as they consider the impacts of this disease and the fight it took to become a survivor. Stories by Ibram Kendi and Mik Awake; photography by Dana Scruggs.

#### **4.4- Patient Case Study: Part 5**

Presented over several modules, this case study follows a patient, parents, and physician through the course of cancer diagnosis, treatment, and survivorship. In Part 5, you will hear from the physician perspective, including the search to find a treatment option that would provide long-term remission and survival for the patient.

##### Lesson Learning Objectives

- State how the patient was able to receive the CAR T-cell therapy despite being older than the clinical trial criteria allowed

- Describe how a national cooperative group, such as the children’s oncology group, is helpful in connecting patients to new treatments

Video run time: 7:26

#### Additional Resources

- [CAR T-Cell Therapy](#)  
This site offers more in-depth information about the therapy discussed in this video. This site is courtesy of the Children’s Hospital of Philadelphia, which was the site of the trial discussed in this video.
- [CAR T Cells: Engineering Patients’ Immune Cells to Treat Their Cancers](#)  
From the National Cancer Institute, this site goes into additional detail about how the CAR T treatment works and how it’s being investigated for use in additional types of cancers.

#### **4.5- Spotlight on Citizen Scientists: Shirley**

This video describes the motivation of a Citizen Scientist to become involved with cancer research, as well as how personal experiences can help shape research.

Video run time: 8:20

#### **4.6- Patient Case Study: Part 6**

Presented over several modules, this case study follows a patient, parents, and physician through the course of cancer diagnosis, treatment, and survivorship. In Part 6, you will hear from the physician perspective, including how this experience is used to help others.

#### Lesson Learning Objectives

- Explain why the physician feels it is a privilege to work with children
- Discuss how the patient and physician use this experience to help others

Video run time: 2:06

## MODULE 5: Social Determinants of Health and Cancer

### 5.1- What are Social Determinants of Health?

This lesson includes information about social determinants of health and catchment areas. Note that this is part 1 of 2, and that the next presentation can be found in lesson 5.2. Some questions to consider while completing this lesson include:

- What are social determinants of health?
- What are catchment areas?
- What factors are considered when determining social vulnerability?

#### Lesson Learning Objectives

- Describe how catchment areas are defined
- Discuss the importance of identifying vulnerable populations in catchment areas
- Provide examples of social determinants of health

Video run time: 6:47

Assessment Questions (Note that correct responses are bolded)

1. Which of the following is true about catchment areas?
  - A. There are only 10 catchment areas in the entire country.
  - B. Patients are responsible for defining their cancer center catchment areas.
  - C. Every cancer center has a catchment area that they define.**
  - D. Cancer centers cannot define their catchment areas.
2. How many counties are included in the UF Health Cancer Center catchment area?
  - A. 52 counties
  - B. 32 counties
  - C. 23 counties**
  - D. 12 counties
3. What are some characteristics of economically distressed counties?
  - A. High levels of poverty and unemployment**
  - B. High levels of income and education
  - C. Low levels of poverty and unemployment
  - D. Low levels of social vulnerability

High levels of poverty and unemployment as well as low levels of income and education are all characteristics of economically distressed counties.

4. Read the following scenario and then select the best answer for the question:  
Connor's family lives in a very unsafe neighborhood. Connor is about to finish middle school and is considering attending high school in a different county because the school is safer and offers some science programs that he is really interested in. However, Connor's parents are concerned about possible moving or transportation expenses related to enrolling Connor in a school outside of their current county. Which social determinants of health are illustrated in Connor's story?
- A. No social determinants of health are presented in this example.
  - B. Social and community context, education access, economic stability, and neighborhood environment.**
  - C. His family's economic stability is the only social determinant of health presented.
  - D. Connor's parents' level of education.

Social and community context, education access, economic stability, and neighborhood environment are important social determinants of health illustrated in the scenario. These social determinants of health are likely to influence health outcomes for Connor and his family.

5. Read the following scenario and then select the best answer for the question:  
Although Noah is still a freshman in high school, he is already making a list of the top 10 best colleges he wants to apply to. Having graduated from top universities, Noah's parents have a very comfortable financial situation and are eager to support his educational experiences. Which social determinants of health are illustrated in Noah's story?
- A. Noah's organization skills.
  - B. Noah's health status.
  - C. Noah's family's level of education and economic stability.**
  - D. Noah's motivation to attend college.

#### Reflection Questions

We suggest giving learners 10 minutes or so to consider these questions and reflect on them. These questions can also be used as a way to facilitate a group discussion about this content.

- Is the topic of social determinants of health new to you?
- Did anything in the video stand out to you?
- How did it make you feel?

## 5.2- Importance of Social Determinants of Health

This lesson includes information about social determinants of health and why they are important. Note that this is part 2 of 2, and that the previous presentation can be found in lesson 5.1. Some questions to consider while completing this lesson include:

- Why are social determinants of health important?
- How do social determinants of health impact health care outcomes?
- Are there specific groups that are more impacted by social determinants of health than others?

### Lesson Learning Objectives

- Provide examples on how social determinants of health can impact health outcomes
- Describe how high social vulnerability can be related to health care outcomes
- Explain how Citizen Scientists can help to incorporate social determinants of health in cancer research projects

Video run time: 6:38

Assessment Questions (Note that correct responses are bolded)

1. Which of the following is true about the relationship between advanced-stage cancer and high social vulnerability areas within the UF Health Cancer Center catchment area?
  - A. Advanced-stage cancer is about 17% lower in areas of high social vulnerability.
  - B. Advanced-stage cancer is about 17% higher in areas of high social vulnerability.**
  - C. Advanced-stage cancer is about 71% higher in areas of high social vulnerability.
  - D. There is no relationship between areas of high social vulnerability and advanced-stage cancer diagnosis.

The research showed that advanced-stage cancer diagnoses are about 17% higher in areas of high social vulnerability within the UF Health Cancer Center catchment area.

2. What are some of the consequences related to an advanced-stage cancer diagnosis?
  - A. The cancer is harder to treat, but the outcomes are promising.
  - B. The cancer is harder to treat and the outcomes are not as good.**
  - C. The cancer is easier to treat and the outcomes are good.
  - D. The cancer is easier to treat, but the outcomes are not as good.
3. What are some topics addressed by questions in the electronic health record at UF Community Health and Family Medicine clinics?
  - A. Transportation barriers
  - B. Financial concerns
  - C. Food insecurity
  - D. All of the above**

4. Read the following scenario and then select the best answer for the question: Mary is a Citizen Scientist interested in social determinants of health and how they relate to cancer treatment and outcomes. In a recent research project, Mary was particularly surprised to find out how many patients in their 40s and 50s did not know how to read. Given Mary's interest and experience, the researchers invited Mary to evaluate screening questions for social determinants of health that are given to patients before each office visit. Which of the following suggestions will Mary likely offer as she revises the questions?
- A. She will suggest for more technical terms to be included.
  - B. She will suggest for more acronyms to be used.
  - C. She will suggest that audio of the text accompany each question.**
  - D. She will suggest the inclusion of advanced statistical analyses to illustrate patient responses through tables and graphs.

An audio mechanism will make the material more accessible both for patients who do not know how to read as well as those who have a visual impairment.

5. Read the following scenario and then select the best answer for the question: Jayden has always been a champion for health care initiatives in his community. Recently, he joined the Citizen Scientist group at his local cancer center and is eager to understand how he can meaningfully contribute to cancer research, especially as it relates to social determinants of health faced by his friends and neighbors. As a more veteran Citizen Scientist, which of the following explanations about how to incorporate social determinants of health into cancer research would you give to Jayden as he begins his time with the group?
- A. We can meaningfully contribute to cancer research by evaluating clinical diagnoses.
  - B. We can meaningfully contribute to cancer research by prescribing alternative medications.
  - C. We can meaningfully contribute to cancer research by providing medical advice to the community.
  - D. We can meaningfully contribute to cancer research by identifying topics that are important to the community.**

We can meaningfully contribute to cancer research, and incorporate social determinants of health into that research, by identifying topics that are important to the community.

#### Reflection Questions

We suggest giving learners 10 minutes or so to consider these questions and reflect on them. These questions can also be used as a way to facilitate a group discussion about this content.

- Is the topic of the importance of social determinants of health new to you?
- Did anything in the video stand out to you?
- How did it make you feel?

## Additional Resources

### [A New Way to Document Social Determinants of Health](#)

This article describes how clinicians at Johns Hopkins Medicine are using tools within their electronic health system to address social determinants of health.

## **5.3- Mapping Cancer Health Outcomes and Disparities**

This video discusses how to use maps to visualize disparities, especially related to cancer, and how to determine when the data has a story to tell.

### Lesson Learning Objectives

- List some factors to pay attention to when reviewing a map
- Discuss how age standardization can play a role in interpreting data from a map

Video run time: 11:34

## Additional Resources

### [United States Cancer Statistics: Data Visualizations](#)

This site allows users to see maps of different cancer metrics (deaths, instances of new cancer) by different variables such as race/ethnicity, sex, type of cancer, and location. The data used in these maps are from the Centers for Disease Control and Prevention and the National Cancer Institute.

## **5.4- Social Determinants of Health in Clinical Practice**

This video offers a real-world view of how social determinants of health can impact a patient's well-being.

### Lesson Learning Objectives

- Identify some economic factors that can influence a patient's health
- Describe how negative influences can impact patient outcomes

Video run time: 2:23

## **5.5- Spotlight on Citizen Scientists: Angela and Nadine**

These videos describe the Citizen Scientist perspective and involvement in a research project related to social determinants of health, including how this experience can shape their role as a Citizen Scientist.

- Video 1 (Angela) run time: 7:41
- Video 2 (Nadine) run time: 7:09

## Final Note

As this is the end of the course, if desired, you can implement internal evaluation tools to help you improve and adjust your curriculum for future cohorts.

We would appreciate your feedback on how you utilized this instructor's guide. Please contact [OneFloridaOperations@health.ufl.edu](mailto:OneFloridaOperations@health.ufl.edu) to notify our team that you have used this content and how you adjusted the curriculum to fit your program's needs.

Thank you for your interest in these resources.

-The University of Florida Citizen Scientist Curriculum Team