

Summative Assessment

INTRODUCTION

Students apply the concepts they have learned during the unit to a case study or other chosen material from the class. From their completed graphic organizers, students choose three concepts to evaluate and explain how the concept contributes to the process of scientific research. Students also communicate the importance of being scientifically literate in their roles as science students, members of society, users of medications, and potential voters and taxpayers.

CLASS TIME

One class period of 55 minutes to begin; it may be continued as homework, if desired.

KEY CONCEPTS

- The process of scientific research requires active participation from scientists, consumers, and citizens.
- A scientifically literate person has a clear understanding of the social nature of scientific research, including the practices and processes involved.
- The ethical conduct of scientific research leads to a process that promotes accountability, integrity, and intellectual honesty.

LEARNING OBJECTIVES

Students will be able to:

- Demonstrate their ability to identify and apply their roles and responsibilities as scientifically literate citizens in multiple venues.
- Define three concepts, identify the importance of each, and give examples of their applications.

MATERIALS

Materials	Quantity
Student Handout— <i>Case Study: Searching for a Cause</i>	1 per student
Optional: Student Handout— <i>Case Study Supplementary Information</i>	1 per student
Student Handout— <i>Summative Assessment</i>	1 per student
Completed <i>Unit Graphic Organizer</i> from the <i>Formative Assessment</i> activity	1 per student
Teacher Resource— <i>Summative Graphic Organizer</i>	1
Teacher Resource— <i>Scoring Rubric for Summative Assessment</i>	1

Scientific literacy is the knowledge and understanding of scientific concepts and processes required for personal decision making, participation in civic and cultural affairs, and economic productivity.

~National Academy of Sciences

NOTE TO THE TEACHER

Use the *Summative Assessment* to assess student understanding of concepts presented in the lessons in this curriculum. Use Teacher Resource—*Scoring Rubric for Summative Assessment* to score student responses.

TEACHER PREPARATION

- Make copies of *Student Handouts*, one per student.

PROCEDURE

1. As the assessment requires a completed *Unit Graphic Organizer* (from the *Formative Assessment*), make sure that students have written in the necessary ideas and concepts for each column. A completed copy can be found on Teacher Resource—*Summative Graphic Organizer*.
2. Pass out copies of Student Handout—*Case Study: Searching for a Cause*, one per student. Allow time for students to read the case study.
3. For teachers or students wanting more depth, pass out the supplementary information found on Student Handout—*Case Study Supplementary Information*.
4. Pass out copies of Student Handout—*Summative Assessment*, one per student. Follow the instructions on the handout.
5. Students should be encouraged to present the information in a way that best suits them, such as an essay, a PowerPoint presentation, a Prezi, or a speech. You may allow students to choose their own medium, or you may choose the format that you want students to use.

GLOSSARY

Advocacy group: An interest group working on behalf of a particular cause.

Blinded study: A study in which researchers do not know which samples are from patients with a disease (in this case, CFS) and which samples are controls from healthy individuals.

Hypochondriac: A person who is convinced he or she is ill, or will become ill, even though there is no disease.

Lobby: To attempt to influence public officials and legislators to promote a specific cause.

Randomization (randomized): The process of assigning study participants to two or more alternative treatments by chance, such as by flipping a coin or rolling a dice.

Replicate: To reproduce or duplicate; to achieve the same study results by following the same study protocol.

Retract: To formally take back or withdraw a statement as invalid.

Retrovirus: Any of a group of viruses that store genetic information as RNA, not DNA. HIV is an example of a retrovirus.

Study design: A strategic approach to carrying out medical research, often involving “blinding” researchers and participants, randomizing samples, and using placebos (fake “sugar pills”) when applicable.

SOURCES

Callaway, E. (2012). The scientist who put the nail in XMRV’s coffin. *Nature*. Retrieved from <http://www.nature.com/news/the-scientist-who-put-the-nail-in-xmrv-s-coffin-1.11444>

Center for Disease Control and Prevention, *CFS case definition*. Retrieved from <http://www.cdc.gov/cfs/case-definition/index.html>

Cohen, J., and Enserink, M. (2011). False positive. *Science* 333, 1694-1701.

Marcus, A. D. (2011). Scientist who led XMRV research team let go. *Wall Street Journal Health blog*. Retrieved from <http://blogs.wsj.com/health/2011/10/03/scientist-who-led-xmrv-research-team-let-go/>

STUDENT HANDOUT

Case Study: Searching for a Cause

Name _____ Date _____ Period _____

Something was wrong. I was sleeping for hours but waking up exhausted. I had fevers, muscle aches, and headaches—I felt like I had the flu, but it just wouldn't go away. This went on for weeks, which turned to months, then years. My forgetfulness, irritability, and fatigue were causing problems at home, at school, and at work. The doctors I visited were concerned, but test after test could not confirm a diagnosis. Some doctors treated me like I was a **hypochondriac**, or like my symptoms were all in my head.

After years of suffering, I was finally diagnosed with Chronic Fatigue Syndrome (CFS). I was relieved to have a name to put with my symptoms, and it helped to be able to give my friends and family the name of **something**. Unfortunately, nobody knows what causes CFS and there are no specific tests to diagnose the condition. Worse, some in the medical community still don't recognize CFS as a "real" medical condition and refuse to treat it. Looking for support and direction, I joined a patient **advocacy group** of people suffering with CFS, their families, and caregivers. Together, we are trying to change attitudes about CFS and **lobby** for increased funding for research.

There can be no cure for CFS without first finding a cause. In 2009, we had some exciting news: Judy Mikovits from the Whittemore Peterson Institute (WPI) published an article in the respected journal *Science* showing that a **retrovirus** was found in blood samples of the majority of the CFS patients she examined. Mikovits and her Nevada-based team had collaborated with three other partners in the U.S. to publish the study. The study findings were exciting to both the scientific and CFS communities.

While the publication in *Science* seemed promising and was considered a "game changer" by advocacy groups, other scientists became skeptical when reviewing the data. Even the peer-review process for publication brought up a number of concerns, such as the possibility of patient samples being contaminated by the retrovirus. This, along with other reservations, was addressed by Mikovits and her co-authors before publication. Nevertheless, after publication a research group from London wrote to *Science* addressing what they considered to be flaws in the paper. Among other things, they pointed out flaws in the study design: Mikovits and her team had not **randomized** and **blinded** patient and control samples. In addition, all of the CFS patients were from Nevada and all of the healthy controls were from elsewhere; perhaps there was an environmental explanation.

With these concerns aired, a number of research teams attempted to **replicate** the data. That's when my hopes for a link between the retrovirus and CFS started to fade. The British team reported that they could not find the retrovirus in **any** of their CFS patients. Two more negative reports followed, then others. Amidst the accusations and criticisms, however, Judy Mikovits would not back away from her claim. She was steadfast in defense of the work and the methods she and her team used to get their results. When asked to voluntarily **retract** her paper from *Science*, she refused. As a person with CFS, I didn't know what to think. Judy Mikovits had worked tirelessly for so long to find a cause of CFS and it seemed to me she was being harassed by the scientific establishment. It was hard to watch my patient advocacy group—a group so hungry for progress—torn apart by the conflicting reports.

The U.S. government-funded National Institutes of Health (NIH) stepped into the debate during this time, contributing \$2.3 million to fund a study to test 150 samples from CFS patients. A solid **study design** was decided upon and the samples were sent to multiple labs throughout the U.S. After waiting impatiently, we were discouraged to read that the study results showed there is no evidence to support the link between the retrovirus and chronic fatigue syndrome. Even before the results were released, the journal *Science* fully **retracted** Judy Mikovits's article from 2009.

I wish I could say the story ended there, but it doesn't. Judy Mikovits was ordered to turn over lab materials to another scientist at the institute and refused. She was fired from her job as research director at WPI. She was then accused of stealing notebooks from the institute, was arrested, and even jailed for a short time. She still stands by her work, however. While an outsider now among scientists, she is a hero for many in the CFS community.

Some people think this whole saga shows what is wrong with science—in this case, poor **study design**, contamination in the lab, refusing to share data, strong personalities, and lots of money leading to conflicting evidence and a confusing message. But I also see how it shows that science **is** working. It shows how collaboration, communication, and skepticism play out. It shows how citizen groups and social forces influence science. It shows the need for new cures and treatments and how basic science gets the ball rolling. It also puts a human face on the research endeavor for me—scientists are people invested in their work. In the end I have to hope that this process will, eventually, find a cause and then a cure for CFS. Because I still wake up in the morning exhausted.

This summary is based on a true story. Please see the **Sources** section of the lesson plan for source information.

Case Study Glossary

Advocacy group: An interest group working on behalf of a particular cause.

Blinded study: A study in which researchers do not know which samples are from patients with a disease (in this case, CFS) and which samples are controls from healthy individuals.

Hypochondriac: A person who is convinced he or she is ill, or will become ill, even though there is no disease.

Lobby: To attempt to influence public officials and legislators to promote a specific cause.

Randomization (randomized): The process of assigning study participants to two or more alternative treatments by chance, such as by flipping a coin or rolling a dice.

Replicate: To reproduce or duplicate; to achieve the same study results by following the same study protocol.

Retract: To formally take back or withdraw a statement as invalid.

Retrovirus: Any of a group of viruses that store genetic information as RNA, not DNA. HIV is an example of a retrovirus.

Study design: A strategic approach to carrying out medical research, often involving “blinding” researchers and participants, randomizing samples and using placebos (fake “sugar pills”) when applicable.

STUDENT HANDOUT

Case Study Supplementary Information

Name _____ Date _____ Period _____

Optional supplementary case study information:

- The retrovirus reported by Mikovits and her partners is a mouse retrovirus called XMRV. This stands for Xenotropic murine leukemia virus-related virus.
- Over the years, many different viruses have been evaluated as the cause of CFS. The scientific community had considered, and dismissed, Epstein-Barr virus, Adenovirus, HTLV I and II, plus others as the cause of CFS. The hopes of people with CFS and their families have been raised and dashed many times already. This string of disappointments has made many people cautious.
- In their letter to the journal *Science*, the British team noted that it was odd that so many CFS patients were infected with the identical virus, since CFS is such an ill-defined syndrome with so many types of people affected.
- The institution where Judy Mikovits worked, Whittemore Peterson Institute for Neuro-Immune Disease (WPI), was founded by the Whittemore family after the diagnosis of their 12-year-old daughter with CFS.
- A test to detect XMRV in a patient's blood was produced, and a commercial lab offering the test opened in Nevada with financial support from the Whittemore family. The cost of the test is about \$500. This drew some criticism, as the people behind the institute supporting the XMRV-CFS link were also the people to benefit from a costly test for the retrovirus.
- Some people with CFS who tested positive using the XMRV test proceeded to use anti-retroviral drugs already FDA-approved for HIV and AIDS patients.

STUDENT HANDOUT

Summative Assessment

Name _____ Date _____ Period _____

Throughout this unit we have explored the practices and processes of scientific research. We have seen the interconnection between the research process, the relationship between science and society, translational research, and what it means to be a scientifically literate citizen.

Using your completed graphic organizer as your guide, choose **three concepts** from the graphic organizer to expand upon. Choose one element from the "Research Process" section (first column), one from the "Role of Science and Society" section (second column), and one from the "Translational Research" section (third column). For each of your chosen concepts:

- a. **Define** the concept (what does the word mean?)
- b. **Identify** its importance (how and why is it necessary?)
- c. **Give a real-world example** of how it is applied (or, inversely, a real-world example of repercussions if it is not applied correctly).

You may use the assessment case study, "Searching for a Cause," or any other materials you have used or learned during this unit to help you with the assessment (see below).

The closing of your assessment should address **the importance of being a scientifically literate citizen** (fourth column of the graphic organizer). How does what you've learned apply to your role as a science student, a member of society, a user of medications and treatments, a potential taxpayer, and a future voter?

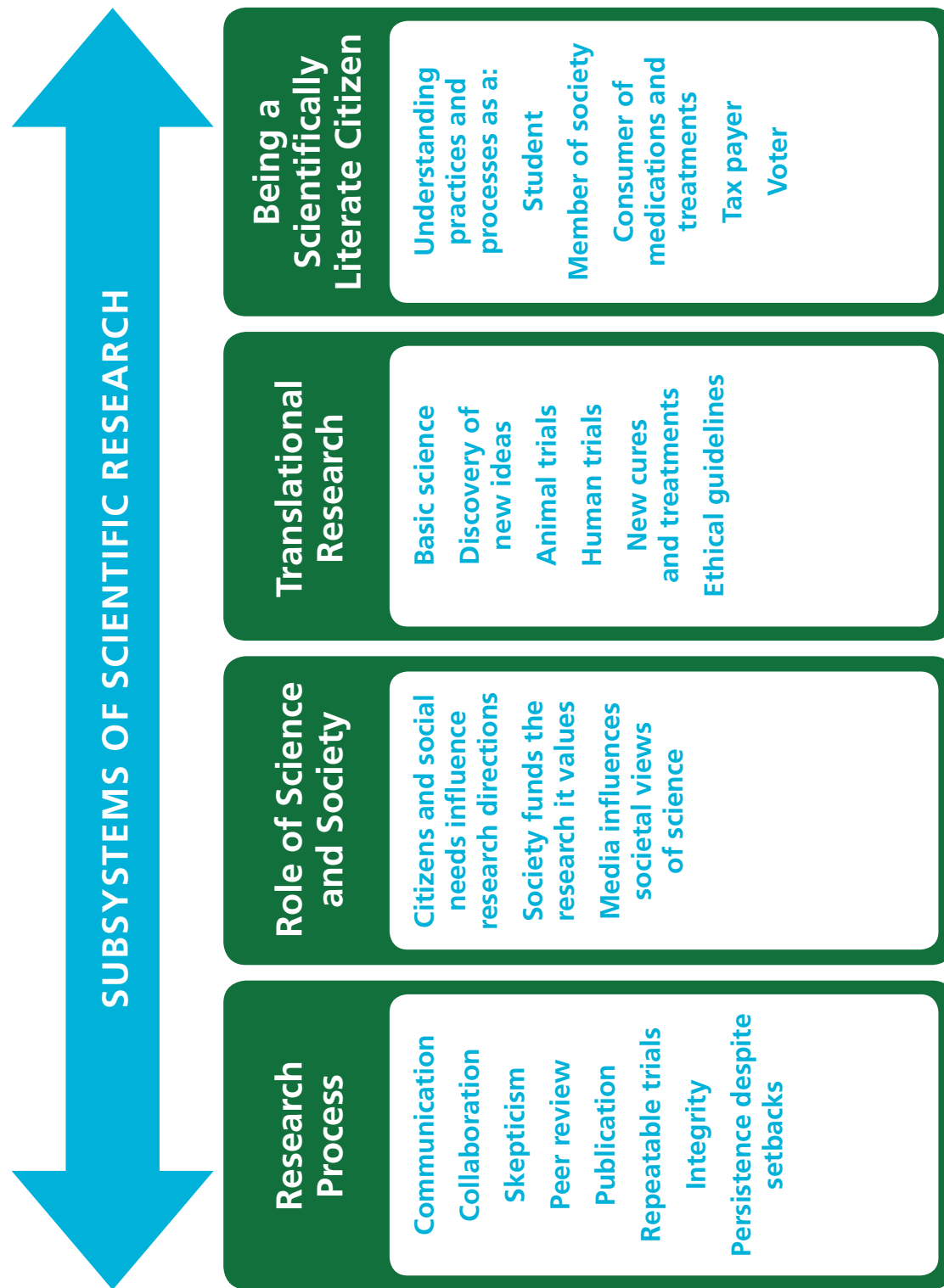
Complete answers should be supported with examples from classroom discussions, activities, and readings, as well as specific examples of actions you can take to demonstrate the need for scientific literacy. Use the attached scoring rubric to guide you in completing this assignment.

You may choose to show what you know through an essay, a PowerPoint presentation, a speech, a Prezi, or other medium (or your teacher will choose the assessment format).

Other possible sources of information include:

Brody, J. E. (2010 January 18). Living with a formerly fatal blood cancer. *The New York Times*. Retrieved from http://www.nytimes.com/2010/01/19/health/19brod.html?_r=1

Nowell, P. C. (2007). Discovery of the Philadelphia chromosome: A personal perspective. *The Journal of Clinical Investigation* 117 (8) 2033-35. Retrieved from <http://www.jci.org/articles/view/31771>



Exemplary	Proficient	Partially proficient	Developing
Using the graphic organizer, student is able to define four concepts, identify their importance, and give examples of their applications.			
<p>Concepts are well-defined.</p> <p>Student accurately uses vocabulary and has numerous examples to explain the importance of the concepts and their applications in an authentic, clear, and easily understood manner.</p>	<p>Concepts are well-defined.</p> <p>Student accurately uses vocabulary and some examples to explain these concepts and their applications in an authentic, clear, and easily understood manner.</p>	<p>Concepts are partially defined.</p> <p>Student accurately uses vocabulary and examples to explain these concepts and their applications but is lacking authenticity, clarity, and/or contains minor errors in understanding.</p>	<p>Concepts are poorly defined.</p> <p>Student uses vocabulary and examples to explain these concepts and their applications but is lacking authenticity, clarity, and contains major errors in understanding.</p>
Student is able to apply and interpret his role as a scientifically literate citizen by identifying and explaining how his actions in multiple settings will reflect his knowledge of the process of scientific research.			
<p>Explanation shows a deep understanding, is authentic, clear, and easily understood, and accurately uses images, anecdotes, and/or analogies.</p>	<p>Explanation is authentic, clear, and easily understood and accurately uses images, anecdotes, and/or analogies.</p>	<p>Explanation uses images, anecdotes, and/or analogies, but is lacking authenticity and/or clarity.</p> <p>Contains minor errors in understanding.</p>	<p>Explanation uses images, anecdotes, and/or analogies, but is lacking authenticity and/or clarity.</p> <p>Contains major errors in understanding.</p>