

**Citizen Scientist Curriculum:
Instructor Guide**

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Overview

Thank you for your interest in the University of Florida Citizen Scientist 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. The certification program is not required, though it is suggested as a way to formalize the learning and offer “bankable” skills to participants. 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.

Lesson Components

The additional lesson components included in this guide are:

- Group Discussion Questions- Suggested open-ended questions that will help participants discuss the topic in greater detail. Instructors should review the questions and be prepared to address participant responses to these questions. 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.
- Group Activities- Exercises to help participants apply the lesson contents to a real-world situation. These activities range from simple group icebreakers to role play activities. In some, research articles are used to help readily identify lesson topics in scientific settings. These activities would be best in an in-person setting; however, instructors may modify the activities to suit an online format if necessary.
- Additional Resources- extra resources, in addition to those listed in the online lesson contents, that can help participants better understand the lesson topic. These are typically research articles or web sites, though an additional open educational resource (OER) web site is used as well. 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 group discussion questions and activity listed in lesson 1.2 should only be implemented once participants have completed the lesson on their own. 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 discussion questions and activities.

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 with the curriculum contents, this guide is an OER and can be edited to fit the needs of individual sites.

For Researchers

To help researchers understand the breadth of what knowledge the Citizen Scientists will have following their completion of the course, this list was compiled. To help Citizen Scientists in their work, an introductory level background was offered on the following topics:

- Citizen Scientists and community stakeholders
- Intellectual property and confidentiality
- Research ethics, including IRB, human subjects research, and informed consent
- Consent for research vs consent for clinical care
- Steps in a basic research study
- Federal funding for research
- How to read a research article
- Types of research studies
- Translational science
- Cultural competency and diversity in research
- Biomedical informatics and big data
- Big data's role in health care

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 in-person discussions are shown in Tables 1 and 2. In these examples, the group meets in person on Fridays, and each meeting's discussion focuses on the lesson(s) they completed earlier in the week. At the conclusion of each in-person meeting, the next lesson(s) is assigned to be completed prior to the next 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 1.1, 1.2	Lessons 1.1, 1.2	Lessons 1.3, 1.4 , 1.5
Week 2 (Fri- Thurs)	Lessons 1.3, 1.4 , 1.5	Lessons 1.3, 1.4 , 1.5	Lesson 2.1
Week 3 (Fri- Thurs)	Lesson 2.1	Lesson 2.1	Lesson 2.2
Week 4 (Fri- Thurs)	Lesson 2.2	Lesson 2.2	Lesson 2.3
Week 5 (Fri- Thurs)	Lesson 2.3	Lesson 2.3	Lessons 2.4 , 2.5
Week 6 (Fri- Thurs)	Lessons 2.4 , 2.5	Lessons 2.4 , 2.5	Lesson 3.1
Week 7 (Fri- Thurs)	Lesson 3.1	Lesson 3.1	Lesson 3.2
Week 8 (Fri- Thurs)	Lesson 3.2	Lesson 3.2	Lessons 3.3 , 3.4
Week 9 (Fri- Thurs)	Lessons 3.3 , 3.4	Lessons 3.3 , 3.4	Lesson 4.1
Week 10 (Fri- Thurs)	Lesson 4.1	Lesson 4.1	Lessons 4.2 , 4.3, 4.4
Week 11 (Fri- Thurs)	Lessons 4.2 , 4.3, 4.4	Lessons 4.2 , 4.3, 4.4	Lesson 5.1
Week 12 (Fri- Thurs)	Lesson 5.1	Lesson 5.1	Lessons 5.2, 5.3, 5.4
Week 13 (Fri- Thurs)	Lessons 5.2, 5.3, 5.4	Lessons 5.2, 5.3, 5.4	Lesson 6.1
Week 14 (Fri- Thurs)	Lesson 6.1	Lesson 6.1	Lessons 6.2, 6.3, 6.4
Week 15 (Fri- Thurs)	Lessons 6.2, 6.3, 6.4	Lessons 6.2, 6.3, 6.4	Lesson 7.1
Week 16 (Fri- Thurs)	Lesson 7.1	Lesson 7.1	Lesson 7.2
Week 17 (Fri- Thurs)	Lesson 7.2	Lesson 7.2	Lessons 7.3, 7.4
Week 18 (Fri- Thurs)	Lessons 7.3, 7.4	Lessons 7.3, 7.4	

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	Module 6
Week 6 (Fri- Thurs)	Module 6	Module 6	Module 7
Week 7 (Fri- Thurs)	Module 7	Module 7	

Completion of the course

As discussed in Lesson 1.1, this course was created with built-in certification levels as participants work their way through the course. Not each participant will need or want to achieve full certification, and these intermediate levels of certification offer an opportunity to build skills in basic areas of research.

Contact

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

The University of Florida Citizen Scientist Curriculum Team

OneFloridaOperations@health.ufl.edu

MODULE 1: Welcome and Orientation

1.1 - Welcome and Program Vision

This initial lesson included an introduction to the curriculum program, and a description of how the program is set up. Also discussed were different levels of certification that a participant can achieve through the course of this training program.

Pre-Lesson Thought Questions

- What is an Open Educational Resource?
- What is my desired level of engagement as a Citizen Scientist?
- What type of activities can I expect in the Citizen Science program?

Lesson Learning Objectives

- Introduce learners to the Citizen Science program
- Discuss the Citizen Science curriculum as an Open Educational Resource
- Describe the activities involved in the Citizen Science curriculum

Video run time: 4:37

Group Activity: Let's Break the Ice!

If this is the first time the group is meeting in person, an icebreaker activity is suggested for this point in the training to facilitate a sense of camaraderie among new group members. This icebreaker activity is only a suggestion- you can use whatever activity you want.

Ask the group to sit in a circle. Write 20 'if' questions on cards and place them (question down) in the middle of the circle. The first person takes a card, reads it out and gives their answer, comment, or explanation. The card is returned to the bottom of the pile before the next person takes their card. This is a simple icebreaker to get people talking and listening to others in the group. Keep it moving and don't play for too long. Write your own additional 'if' questions to add to the list, or have group members contribute questions as well.

'If' questions (adapted from [the blog "Insight"](#)):

1. If you could go anywhere in the world, where would you go?
2. If I gave you \$10,000, what would you spend it on?
3. If you could only speak one language other than English, what would it be?
4. If you could talk to any living person in the world, who would it be?
5. If you could wish one thing to come true this year, what would it be?
6. If you could live in any period of history, when would it be?
7. If you were an animal, which would you be?
8. If you could be someone else for a day, who would you be?
9. If you could get the answer to any unsolved mystery, what would it be?
10. If you won a lifetime supply of any item, what would it be?
11. If you could have any kind of pet, what would you have?
12. If you could do your dream job, what would it be?
13. If you could travel ahead in time, what point in time would you visit?
14. If you were able to speak to yourself 10 years ago, what would you talk about?
15. If money and time was no object, what would you be doing right now?
16. If you had one day to relive, what day would you pick?
17. If you could only eat one food item for a whole year, what would it be?
18. If you could learn any skill, what would it be?
19. If you were sent to live in space for six months and were only allowed to bring three personal items with you, what would they be?

20. If you had to repeat a grade or year of school, which would you choose?

1.2 - Citizen Scientists: Who are they? What do they do?

This lesson contained an overview of Citizen Scientist programs including what team members may be asked to do and the evolution of citizen science in society.

Pre-Lesson Thought Questions

- What is the role of a Citizen Scientist in society?
- Who can be a Citizen Scientist?
- What are common activities in which a Citizen Scientists can engage?

Lesson Learning Objectives

- List some of the activities in which Citizen Scientists may engage
- Describe the role Citizen Scientists may play in influencing research priorities and development
- Discuss an example of how Citizen Science has furthered the research of a rare disease

Video run time: 8:26

Assessment completion time: 10 minutes (approximate)

Group Discussion Questions

- Have you ever seen (or taken part in) a Citizen Science activity in any other field?
- Why may it be beneficial to include citizens in data collection (in fields like weather or nature) or research proposal review?
- What may be a challenge in including Citizen Scientists in a clinical research project?
- Can you think of a field where it would NOT be beneficial to either the community or researchers to include Citizen Scientists?

Group Activity: Journal Club

In the same style as a journal club gathering, instruct participants to seek out a news or journal article about citizen science and read it over. Have them bring a copy of the article to the group session and be prepared to discuss what contributions citizen scientists made to the project. This can be done for any field and does not need to be health care-oriented.

Additional Resources

- Terry, S. Learning Genetics. *Health Affairs*, 22(5), 166-171.

1.3 - New Employee Orientation (Site-specific content)

This lesson offers a chance to review new employee information for Citizen Scientists.

Items that could be in this site-specific orientation include:

- Program expectations
- Background information on the institution, department, and program
- Organizational charts and reporting structure
- Key terms, acronyms, and glossary
- Online account access instructions
- Payroll and benefits information

- Meeting schedules and procedural information
- Required trainings from the institution and how to access them
 - Can be listed here and/or under the module lesson most applicable to the training (for example, a required HIPAA training can be paired with Lesson 1.4- Intellectual Property and Confidentiality)

1.4 - Intellectual Property and Confidentiality

This lesson discussed the concept of intellectual property, as well as practicing confidentiality as a Citizen Scientist.

Pre-Lesson Thought Questions

- What is intellectual property and how do I, as a Citizen Scientist, protect it?
- What is confidentiality and how do I practice it as a Citizen Scientist?
- When should I treat information as confidential?

Lesson Learning Objectives

- Describe the concept of intellectual property
- Recognize intellectual property and treat it as confidential
- Explain why it is important to researchers that their work is treated with confidentiality

Video run time: 6:20

Assessment completion time: 15 minutes (approximate)

Group Discussion Questions

- What type of information can be freely shared?
- What may be a consequence of revealing confidential information from a researcher, study participant, or research study?

Additional Resources

- University of California, Irvine: Office of Research- Privacy and Confidentiality- <https://research.uci.edu/human-research-protections/research-subjects/privacy-and-confidentiality/>

1.5-Citizen Scientists in Action: Forming a Mission Statement

In this lesson, a University of Florida Citizen Scientist shared an overview of the process the group utilized to come up with a mission statement.

Video run time: 5:18

Group Discussion Questions

- Why would a group of Citizen Scientists need a mission statement?
- What may be a benefit to having members of a Citizen Scientist group create their own mission statement (as opposed to having leadership draft it for them)?

Additional Resources

- Community Toolbox: Developing a Strategic Plan- <http://ctb.ku.edu/en/table-of-contents/structure/strategic-planning>

MODULE 2: Research Ethics

2.1 - IRBs and Human Subjects Research

This lesson covered the basic makeup and tasks of the Institutional Review Board (IRB), and types of approval processes used to grant research study approval.

Pre-Lesson Thought Questions

- Why do IRBs exist?
- What would research be like without IRBs?
- If I had been one of the participants treated unethically in past research, would the current participant protections make me feel at ease?

Lesson Learning Objectives

- Discuss the importance of an IRB
- Express the difference between a human and non-human research subject
- List the different types of IRB approval for research studies

Video run time: 11:06

Assessment completion time: 10 minutes (approximate)

Group Discussion Questions

- Why are IRBs made up of a mix of scientists, non-scientists, and community members?
- What elements of a research protocol could tell the IRB if a study is ethical or not?
- Can you think of any examples of ways a researcher would violate IRB unintentionally?

Additional Resources

- Perrault, E., Nazione, S. Informed Consent— Uninformed Participants. *Journal of Empirical Research on Human Research Ethics*. 11(3), 274-280.

2.2 - Research Ethics

Explained in this lesson was why we have an Institutional Review Board (IRB) and the events that took place that led to the development of the current research subject protections.

Pre-Lesson Thought Questions

- What have been consequences to patients as a result of unethical research?
- Which groups are considered vulnerable populations?
- What is meant by conflict of interest and why does this matter in research?

Lesson Learning Objectives

- Discuss protections now in place to protect research participants
- Identify ethical principles that guide conduct of human subjects research
- Discuss key aspects of research where ethical issues may arise

Video run time: 11:20

Assessment completion time: 10 minutes (approximate)

Group Discussion Questions

- Why is justice a necessary principle in research studies?

- Can you give an example of therapeutic misconception?

Group Activity: You can't do that in Research!

Have group members suggest outlandish, unethical research studies with vulnerable populations (i.e., testing techniques for amputations on prison inmates). The rest of the group will list reasons the proposed study is unethical, as well as how to make the study ethical.

Potential modifications to this activity include providing participants with ethical and unethical research examples then asking participants to classify and discuss the examples or offering research scenarios with a discussion prompt of "This would be unethical if..." and have participants offer their thoughts.

Additional Resources

- Wikipedia: Unethical human experimentation in the United States: https://en.wikipedia.org/wiki/Unethical_human_experimentation_in_the_United_States
- US Department of Health and Human Services: Office for Human Research Protections- The Belmont Report- <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html>

2.3 - Informed Consent

Topics discussed in this lesson were the informed consent process, including necessary elements, types, and special situations such as minors or emergency use.

Pre-Lesson Thought Questions

- What is the role of a Citizen Scientist in society?
- Have I ever received an unclear informed consent form?
- What elements might be necessary to make an informed consent document clear to the participant?
- What steps might a researcher need to take if a potential participant does not speak English?

Lesson Learning Objectives

- Define assent
- Explain the elements of consent
- Describe conditions for which emergency use informed consent would be appropriate

Video run time: 9:49

Assessment completion time: 10 minutes (approximate)

Group Discussion Questions

- Why is it important to have independent guidance from scientists not involved in the research study being discussed? Wouldn't it be best to take into account the opinion of someone who knows the study very well?
- Have you ever read an informed consent form? Was anything unclear? How could it have been improved?

Group Activity: You want me to do what?!

Print the informed consent form below. Note that this is a completely made-up document, and intended for educational purposes only. Have participants go through and identify ways this is a bad informed consent form and how it could be improved to better serve participants.

Informed Consent: Assessment and Interview

Project Title: Adverse Events in Teens

****Please read this consent document carefully before you decide to participate in this study****

Purpose of the research study:

The purpose of this study is to determine the stressors and difficulties teens face. We can fix teens more effectively once we know what's wrong with them, so this work is necessary.

What you will be asked to do in the study:

You will be asked to complete an assessment that asks about adverse situations you may face as a teenager. This can include whether or not you've tried narcotics, if you're sexually active, whether you have an intellectual disability, your weight and height, and whether you've ever been abused by a caretaker. The assessment will be followed up by an in-person interview to discuss your responses to the questions. We will then be posting the responses in an interactive online map that geocodes your responses to your ZIP code and educational institution. By knowing what your life is like both at home and at school, we can identify whether these are common barriers to a normal, happy teenage life.

Time required:

Approximately 90 minutes

Risks and Benefits:

There are no immediate perceived benefits at this time. However, you may feel that speaking about your responses to researchers is cathartic and may feel like a benefit similar to expensive therapy sessions that may otherwise invoke out-of-pocket costs.

Like anything in life, there are some risks. You may feel uncomfortable discussing some topics, and by law, you do not have to discuss any topics you do not wish to discuss, although we would really appreciate it if you answered the entire assessment. Your personal responses will be available for anyone to read online, but it would take a bit of Googling, and frankly stalking, to be able to match up your responses with your school and ZIP code. As long as you don't tell others what you said, your information will likely stay confidential.

Compensation:

You will not be paid for your time; however you will likely feel a sense of pride because you gave us information that can maybe someday help another teenager.

Confidentiality:

Your identity will be kept confidential as long as you don't tell other people what you said. We at the research team won't say anything if you will not. We also will not tell your parents, and as long as you don't either: they don't even need to know you were part of this research study, thus maintaining confidentiality.

Voluntary participation:

Your participation in this study is voluntary, but you should absolutely consider participating, as it can help teenagers like you some day in the future.

Right to withdraw from the study:

You have the right to withdraw from the study at any time without consequence but we strongly urge you not to do so.

Whom to contact if you have questions about the study:

John Smith, PhD, Researcher; adverseteens@hotmail.com

Agreement:

I have read the procedure described above. I voluntarily agree to participate in the procedure and I have received a copy of this description.

Participant: _____ Date: _____

Principal Investigator: _____ Date: _____

2.4- Consent for Research vs Clinical Care

This lesson discussed the differences in agreeing to participate in a research study compared to agreeing to be treated for an illness or injury.

Pre-Lesson Thought Questions

- What are the different types of informed consent for minimal risk research or clinical care?
- For what types of topics might a minor be glad they do not need parental consent?
- How might I react if asked to consent for research in a high stress environment, such as the Emergency Department?

Lesson Learning Objectives

- Identify differences between consent for clinical care and consent for research participation
- Understand the environment in which clinical research is conducted and how consents for clinical care, research, and HIPAA authorization are related
- Apply understanding of consent to real-world examples

Video run time: 7:09

Assessment completion time: 15 minutes (approximate)

Group Discussion Questions

- Why is it important to know the difference between these two types of consent?
- Can you think of reasons someone who was consented into a project by their LAR while incapacitated might be glad that they are able to withdraw consent upon no longer being incapacitated?
- If you were a researcher looking to recruit participants in the Emergency Department waiting room, what sort of challenges would you need to be mindful of when approaching patients and families?

Group Activity: Study Recruitment Role Play

Write these descriptions on pieces of paper and give to three participants. For this exercise, it is crucial that the other participants do not know each other's backstory:

Participant A- You are a researcher trying to determine the best medication to treat an STD in teenagers. You are trying to enroll teens that have an STD and teens that do not have an STD in your study through approaching eligible patients as they wait for the doctor.

Participant B is a 15 year old girl in the exam room with her father, Participant C, and you want to speak to her about participating in the research study. What things do you need to ask them prior to signing her up for the study? How would you present this information?

Participant B- You are a 15 year old girl who is happy to please authority figures. You are not sexually active and have never had an STD. You think health care and research are interesting and want to sign up for this study.

Participant C- You are the father of a 15 year old girl. You deeply mistrust researchers after a bad experience when you were younger. You are having a tough time accepting that your child is a teenager, and have told her that she is not allowed to date until she's 17.

Participant A must approach Participants B and C and try to gauge whether Participant B is interested in participating in the research study while maintaining confidentiality about Participant B's sexual activity.

Role Play Discussion Questions

- How could the researcher have handled this situation more effectively?
- Can you think of a way to present the study information in a clearer manner?
- Was Participant B's personal information protected in an effective way? If not, what could have been done differently?

2.5 - Citizen Scientists in Action: Working as a Citizen Scientist

In this video, Citizen Scientist members discussed what types of activities they work on and expectations of Citizen Scientists as subject matter experts.

Video run time: 5:51

Certification Level 1

Upon Completion of Modules 1 and 2, participants receive the Level 1 Citizen Scientist Certification. Citizen Scientists who obtain Level 1 certification may begin to participate in minimal engagement activities such as reviewing content and design of grant applications, recruitment materials, and consent forms.

Ensure that participants have submitted their certificates before proceeding with the course.

[Certification Form: Level 1](#)

MODULE 3: Sponsored Research

3.1- Research 101

This lesson taught about the topic of research, including the steps in conducting research. This lesson also covered points in the research process where Citizen Scientists can offer invaluable input and actionable advice.

Pre-Lesson Thought Questions

- Why is it important to submit the research plan to the Institutional Review Board?
- Why might it be important to report the study findings back to the community?
- Are there other areas of the research process in which I could offer input?

Lesson Learning Objectives

- Define research
- Restate the steps in the research process
- Cite the steps of the research process for which Citizen Scientist input is most valuable

Video run time: 11:05

Assessment completion time: 10 minutes (approximate)

Group Discussion Questions

- Why could a review of the literature be beneficial to researchers?
- What are some of the different elements of the research plan, and why are they important?
- What may be some of the consequences of not including patients or Citizen Scientists in the review of a proposed research study?

Group Activity: Study Design Creation

Task members with designing a research study using the scientific method. This does not have to be anything sophisticated or scientifically rigorous (see example on the website listed below about making toast), but participants should be able to point out the different steps of the research process when hearing each other's proposed research studies. They should also note when in the process it is ideal to engage Citizen Scientists.

Additional Resources

- Kahn Academy: The Scientific Method-
<https://www.khanacademy.org/science/biology/intro-to-biology/science-of-biology/a/the-science-of-biology>

3.2- Federal Funding for Research

This lesson provided an overview of federal funding sources, and discussed the differences in contracts and grants, as well as the process involved for obtaining research funding.

Pre-Lesson Thought Questions

- Why must multiple people be involved in a submission for federal funding?
- Which federal agencies are most likely to sponsor health care projects?
- What is meant by indirect costs?

Lesson Learning Objectives

- Explain how the process for research funding works
- Cite the difference between a contract and a grant
- List some of the organizations that offer research funding opportunities

Video run time: 11:50

Assessment completion time: 10 minutes (approximate)

Group Discussion Questions

- Why is research funding more complex than simply sending a check to researchers with great ideas?
- Why do you think it's necessary for the institution to submit a grant application instead of the researcher submitting it directly?
- Why is the timeline for awarding grants so long?
- Why don't agency directors just decide who gets the funding instead of dragging in lots of people to review grant submissions?

Additional Resources

- Science Magazine: Where to Search for Funding-
<http://www.sciencemag.org/careers/where-search-funding>

This page has several interesting articles linked that give an overview of some places that list grant opportunities, how to make a strong grant application, and insights from grant reviewers. This information may be very helpful to Citizen Scientists trying to understand this complex process. As a group activity, instructors could assign participants one of the articles, then have them discuss together, or have participants find, present, and discuss an article of their choice.

3.3 - How to Read a Research Article

This lesson included a breakdown of the components of a research article and how to understand what you're reading.

Pre-Lesson Thought Questions

- What is the point of a research article?
- What can reading a research article add to my expertise as a Citizen Scientist?
- In which section will the authors describe the limitations and next steps of the study?

Lesson Learning Objectives

- State the major sections of a research article
- Describe the key points of a research article
- Explain the purpose of the article's abstract

Video run time: 9:10

Assessment completion time: 15 minutes (approximate)

Group Discussion Questions

- Why do researchers write articles?
- Have you ever read a research article before you did this lesson? What was your favorite part of it? What was the part that was hardest to understand?

- If you could require a new section or component that all research articles must include, what would it be and why? (i.e., require a lay abstract, require a “so what” statement)

Group Activity: Name that Section!

As with the additional resource listed in the course contents, have the group read and mark up the different sections of a journal article. Find an article that you are interested in, or one you know well (a short article would be ideal), and mark it up as an “answer sheet” to guide the group discussion. Make sure they note if they feel the study was quantitative or qualitative, and note the key points the article is making. See if the group had the same interpretation of the article (or not) and why.

Additional Resources

- Science Magazine: How to (seriously) read a scientific paper- <http://www.sciencemag.org/careers/2016/03/how-seriously-read-scientific-paper>
- British Medical Journal: How to read a paper- <http://www.bmj.com/about-bmj/resources-readers/publications/how-read-paper>
This link lists several articles in a well-known scientific journal that help explain different elements of reading articles.

3.4 - Citizen Scientists in Action: Research Team Meeting

Citizen Scientist members met with members of a research study team to discuss issues of concern including recruitment strategies and identification of inclusion criteria.

Video run time: 16:30

Group Discussion Questions

- Do you feel the answers given by the research team accurately addressed concerns by the Citizen Scientists? Why or why not?
- Were there any examples of Citizen Scientists offering specific feedback on any part of this study?

MODULE 4: Clinical and Translational Science

4.1 - Translational Sciences 101

This lesson covered what translational science is and the role Citizen Scientists play in this field.

Pre-Lesson Thought Questions

- Other than clinical and medical discoveries, what areas also have a significant impact on health outcomes?
- Why is the research approach called bench to bedside?
- Why did a cure for scurvy take so long to be implemented?

Lesson Learning Objectives

- Describe translational science
- Articulate how a Citizen Scientist can help shape translational science projects
- Explain the ultimate goal of translational science

Video run time: 8:31

Assessment completion time: 15 minutes (approximate)

Group Discussion Questions

- Why should research be translated back into the community in the first place?
- Do you think it's necessary to translate both favorable and unfavorable results? Why?
- Why isn't research as simple as taking a scientific discovery and persuading lawmakers to mandate its use?

Additional Resources

- UCSF Clinical and Translational Science Institute: What is Clinical and Translational Science- <https://accelerate.ucsf.edu/about/clinical-and-translational>

4.2 - Types of Research

This lesson explained different types of research studies that Citizen Scientists are likely to encounter, including the similarities and differences across types.

Pre-Lesson Thought Questions

- How does a pragmatic study differ from a randomized control study?
- For what reasons might a researcher choose to conduct an observational study instead of an experimental study?
- Why would a double-blind study be beneficial to the research team?

Lesson Learning Objectives

- Explain the differences between a randomized control trial and an observational research study
- List an example of comparative effectiveness research
- Discuss the purpose of a pragmatic research study

Video run time: 9:14

Assessment completion time: 10 minutes (approximate)

Group Discussion Questions

- There are things like gold standard study designs, and studies done in an ideal setting. Why don't all studies use the gold standard, or take place in an ideal setting?
- Can you think of any challenges associated with conducting observational studies?

Group Activity: Study Design Pop Quiz

Have the group read a journal article and identify the type of study design utilized. Use the same article you used in the Group Activity in Lesson 3.3 (How to Read a Research Article) or give the group new articles using different designs and see how many they can identify. Have them explain what features of the study made it clear what type of design was utilized.

Additional Resources

- Khan Academy: Statistics: Gathering Data-
<https://www.khanacademy.org/math/statistics-probability/ap-statistics/gathering-data-ap>

4.3 - Case Study: Citizen Scientist Role in Translational Science

This case study offered a glance at the journey a scientific discovery can take from the point of research to improved patient care.

Lesson Learning Objectives

- Describe how translational science gets from the researcher to everyday clinical care
- Discuss the role community members can play in translational science

Video run time: 1:50

Group Activity: A Day Without Citizen Scientists

Share information about a study at your organization that currently involves patient stakeholders or Citizen Scientists. This could be a study that the group is already familiar with. Brainstorm ways the study would be different from its current form without the involvement of patient stakeholders or Citizen Scientists.

4.4 - Citizen Scientists in Action: Research Study Review

Citizen Scientists offer their thoughts on the process involved in reviewing research study components and types of activities for which researchers seek Citizen Scientist input.

Video run time: 6:35

Certification Level 2

Upon Completion of Modules 3 and 4, participants receive the Level 2 Citizen Scientist Certification. Citizen Scientists who obtain Level 2 certification may begin to participate in moderate engagement activities such as consultation on study design, including assisting with research questions, recruitment/retention strategies, and dissemination plans.

Ensure that participants have submitted their certificates before proceeding with the course.

[Certification Form: Level 2](#)

MODULE 5: Stakeholder Engagement

5.1 - What is Stakeholder Engagement?

This lesson included information about stakeholder groups, as well as the value of stakeholder engagement and perspective, particularly from community members.

Pre-Lesson Thought Questions

- How do advocacy groups and stakeholders differ?
- How can I tell if engagement is meaningful?
- Why is stakeholder engagement important?

Lesson Learning Objectives

- Define what is meant by the term “stakeholder”
- Discuss the role a stakeholder can have in a project
- Give examples of stakeholder engagement in the community

Video run time: 7:57

Assessment completion time: 10 minutes (approximate)

Group Discussion Questions

- With so many opinions to balance, why would it be beneficial to include multiple types of stakeholders on projects?
- Who are the most important stakeholders on a project?
- Researcher X has a grant that stipulates that he must involve patient stakeholders on his research team. He does not agree, and is very resistant to this idea, yet must do so to keep his funding. What ways can you think of to make the interaction more meaningful and harmonious, from both his point of view and from the stakeholder point of view?

Group Activity: Name that Stakeholder!

Name possible stakeholders for the following activities:

- A proposed city ordinance to raise taxes on soda
- A research study to determine whether males or females respond best to an inpatient diet and exercise program at a rehab hospital
- A task force that is investigating whether a fresh produce cart on campus has been successful
- A proposal to increase physical activity in school-age children through adding more playgrounds in the community
- A state-funded program aimed at reducing asthma attacks by lowering fossil fuel emissions
- A group offering free infant CPR classes in low-income communities

Additional Resources

- Patient-Centered Outcomes Research Institute (PCORI): PCORI's Stakeholders-
<http://www.pcori.org/funding-opportunities/what-we-mean-engagement/pcoris-stakeholders>

5.2 - Case Study: Stakeholder Involvement in the Belmont Report

This case study provides an overview of stakeholder involvement during the development of the Belmont Report.

Lesson Learning Objectives

- List some of the events leading to the creation of the Belmont Report
- Describe some of the attributes that made this report groundbreaking

Video run time: 9:10

Group Discussion Questions

- Why was it necessary to get a group of citizens (rather than lawmakers) involved in creation of a government report?
- Why was it important that the Commission staff sat at the table and joined discussions with the Commission members?
- The video mentions that it took a long time (of the short timeframe they were given to write the report) to come up with a standardized language because the ethicists, lawyers, and health care professionals all spoke a different language. Why not just let everyone play to their strengths? Why bother having a standardized language if they were up against a deadline?

Additional Resources

- US Department of Health and Human Services: Office for Human Research Protections- Interview with Robert Cooke, one of the National Commission members- <https://www.hhs.gov/ohrp/education-and-outreach/luminaries-lecture-series/belmont-report-25th-anniversary-interview-rcooke/index.html>

5.3 - Citizen Scientists in Action: Teen Citizen Scientist Meeting

Members of the Teen Citizen Scientist group at the University of Florida discussed issues of concern including dental health, confidentiality, and health risk behaviors.

Video run time: 7:37

Group Discussion Questions

- Do you think researchers should address teens differently than adults? Why or why not?
- Can you think of any situation in which the confidentiality of a teenage patient or study participant should be breached?

5.4 - Citizen Scientists in Action: Offering Input on Projects

This video offered a look at how Citizen Scientist input on a proposed study helped shape the research plan, and describes how the research benefited from this input.

Video run time: 1:01

MODULE 6: Cultural Diversity in Research

6.1 - Cultural Competence

This lesson described the broad concept of cultural competency and how Citizen Scientists can ensure their perspectives are represented and respected in research studies.

Pre-Lesson Thought Questions

- What beliefs, practices, or experiences have contributed to my own cultural background?
- Have I ever felt misunderstood because another person did not understand my culture?
- How can I work to identify my implicit biases?

Lesson Learning Objectives

- Define cultural competency
- Cite examples of cultural competency in health care
- Give an example of how a Citizen Scientist can ensure their culture, gender, race, or age group is respected in a research study

Video run time: 14:32

Assessment completion time: 15 minutes (approximate)

Group Discussion Questions

- Why is it important to take other cultures into consideration when conducting research?
- Please share an example of a practice or tradition specific to your culture. This can be an ethnic, neighborhood, religion, educational, or family culture. Examples: when University of Florida graduates meet, they do a “gator chomp” at each other; the Hindu festival Diwali is celebrated in the fall with fireworks, lamps, lanterns, and bright colors to symbolize the triumph of light over darkness; every year in August, many neighborhoods in Chicago host block parties to help the residents get to know each other better and so children can have fun before the school year begins.
- If you feel comfortable, please share a time when someone else misunderstood you because of differing cultural experiences or implicit biases. What could the other person have done differently to be more culturally competent?

Additional Resources

- Community Toolbox: Enhancing Cultural Competence-
<http://ctb.ku.edu/en/enhancing-cultural-competence>

Group Activity: Tip of the Iceberg (Adapted from the Innovation and Leadership Platform website via Concordia University, 2016)

Ask participants to draw an iceberg and list different components of their individual culture within the two parts of the iceberg. The part above water will include objective facts about the person; that is, all the observable traits others can readily identify (example: skin color, name, accent, religious attire or jewelry, diet). The part under the water will be for the subjective things that are not easily seen by others (example: fears, beliefs, habits, living situation, holistic behaviors). Have the group share their drawings and discuss how we all have traits hidden under the surface and can only see them if we look beyond what’s staring back at us. These traits can be similar, and someone whose objective traits might not be inviting may be able to add a lot to a project or situation based on their subjective traits.

6.2 - Case Study: Culture of Science

This video provided a description of the culture of science and academia and how Citizen Scientists can navigate this new environment.

Lesson Learning Objectives

- List attributes of the research community culture
- Describe how Citizen Scientists can help interpret research to the broader community

Video run time: 5:35

Group Discussion Questions

- What are some ways that we can respect the members of the culture of science?
- Think of a time when you felt frustrated with a researcher or health care professional. Given what you now know about the culture of science, do you think this could explain the misunderstanding? If you could go back, what would you do differently in the interaction?

6.3 - Case Study: Diversity in Clinical Trials

In this video, created by the US Food and Drug Administration as part of its “Year of Clinical Trial Diversity”, a stakeholder living with sickle cell disease explained the importance of diversity in clinical trials.

Lesson Learning Objectives

- Explain the importance of including a diverse population in a clinical trial
- Discuss a potential consequence of not including a minority group in a clinical trial to test a new drug

Video run time: 2:00

Group Discussion Questions

- When examining specific diseases, do you think it's important to include both participants with and without the disease? Why?
- Provide an example of what it means to include a diverse group of participants in a study (ex: different gender, ethnicities, socioeconomic status, disease status)

6.4- Citizen Scientists in Action: Importance of Diversity

This video detailed the importance of having members of a Citizen Scientist group with opposing viewpoints, backgrounds, and life experiences.

Video run time: 4:18

Group Discussion Questions

- Do you think it's possible to have a successful group (in any field, in any scenario) without diversity in the participants? Why?
- What sort of diverse differences are present within our group? (ex: difference in gender, age, education, religion, politics, expertise, interests)

MODULE 7: Biomedical Informatics

7.1 - Biomedical Informatics and Big Data

This lesson described the terms bioinformatics and big data. Also discussed were ways this field can be used to improve life and answer questions.

Pre-Lesson Thought Questions

- What makes big data big?
- How can researchers conquer some of the challenges posed by collecting big data?
- How can big data applied to precision medicine improve health care?

Lesson Learning Objectives

- Describe the difference between computer science and bioinformatics
- List some of the areas in which big data can improve life
- Outline a challenge faced with collecting big data

Video run time: 7:00

Assessment completion time: 15 minutes (approximate)

Group Discussion Questions

- Where in your life have you come across big data? (Examples: any time you search for something on Google, when Netflix suggests a movie you may enjoy, logging in to your patient health care records through your health care system's web portal, how highway authorities know how many cars pass a certain point every year)
- In what other fields do you think big data can be helpful to society? Give some examples.
- Why is it a problem if the data received are not in the same format from multiple sources?

Group Activity: Explaining Big Data

You are a researcher looking at whether use of a long-term medication makes an improvement on migraines. You are trying to collect data from across multiple health care systems around the country, and need to present to a group of Citizen Scientists what you're doing, why, and how it will benefit patients. What sort of questions do you think they will have about big data and the purpose of this study? How would you address their concerns?

Additional Resources

- Cincinnati Children's Hospital: Biomedical Informatics: Where Discoveries Save Lives- <https://www.youtube.com/watch?v=WcjNGoAVBtQ>
- Ted Talk: TEDxRVA- Biomedical Big Data Revolution, Dr. Stefan Bekiranov- <https://www.youtube.com/watch?v=kyMzPwS88F8>
- Ted Talk: TEDxBeaconStreet- Big Data Meets Cancer, Neil Hunt- <https://www.youtube.com/watch?v=IWu6XWzbPBs>

7.2 - Big Data in Health Care

This lesson provided concrete examples of big data being used to help improve health care.

Pre-Lesson Thought Questions

- Do I currently use any methods of collecting big data?
- Have I ever shared big data with others through traditional or non-traditional methods?
- Are there other ways to possibly apply big data to health care, in an effort to improve patient health outcomes?

Lesson Learning Objectives

- Describe a reason for which a researcher might want to pull patient data
- Explain how big data can positively impact health care
- Cite an example of big data in use

Video run time: 8:36

Assessment completion time: 10 minutes (approximate)

Group Discussion Questions

- Do you think you have ever shared big data with researchers? Why do you say yes or no?
- How is big data useful in health care?

Group Activity: Big Data Head Count

Have the group guess how many items in the room collect big data. Have them say their numerical guess, then go through and count. It's important to count both devices (smartphones, iPads, fitness trackers, medical devices, etc.) as well as the applications on those devices that collect data (Netflix, Facebook, Instagram, MyFitnessPal, etc). What data do these items collect, how, and why?

Additional Resources

- Devex, December 13, 2016: How Facebook statuses informed the Zika response in Brazil- <https://www.devex.com/news/how-facebook-statuses-informed-the-zika-response-in-brazil-89290>
- Forbes, April 21, 2015: How Big Data is Changing Healthcare- <https://www.forbes.com/sites/bernardmarr/2015/04/21/how-big-data-is-changing-healthcare/#3a46ec5c2873>
- Modave, F. et al. DiaFit: The Development of a Smart App for Patients with Type 2 Diabetes and Obesity. *Journal of Medical Internet Research Diabetes*, 1(2), e5.

7.3 - Case Study: Big Data's Journey Through Health Care

This video illustrated the journey health care data takes from the time it is entered into a patient medical record to the point where it may get pulled as part of a large research data set.

Lesson Learning Objectives

- Describe the need for a standardized language across data sets
- Explain how health can be improved by merging data from multiple patient records

Video run time: 5:16

Group Discussion Questions

- Think back to the example shown in the video about having two different doctors in two different health systems. Have you ever experienced this? What could be a challenge in this situation? Examples: harder to get records from a long time ago (i.e., vaccination records from 10 years ago); if you don't know the name of a drug you're on and your health care records aren't linked, a newer doctor can put you on something that may interact with a medication you're already taking.

7.4- Citizen Scientists in Action: Sustained Engagement Activities

This video described the work Citizen Scientists do through sustained engagement, including work done on a national level through appointments to national workgroups.

Video run time: 5:16

Group Discussion Questions

- Can you think of any additional skills, training, or expertise a Citizen Scientist might need to engage in some of these sustained engagement activities?
- What may be some challenges Citizen Scientists face as they engage in some of these more engaged activities?

Certification Level 3

Upon Completion of Modules 5, 6, and 7, participants receive the Level 3 Citizen Scientist Certification. Citizen Scientists who obtain Level 3 certification may begin to participate in sustained engagement activities such as participation in workgroups and committees, organizational representation at meetings or conferences, or serving as a member, co-author, or co-presenter of a research study team.

Ensure that participants have submitted their certificates.

[Certification Form: Level 3](#)

Final Note

This is the final step in the course. At this part 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 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