

Using Instructional Design Principles to Engage Citizen Scientists as Clinical Research Partners

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OneFlorida Overview

- **Statewide collaboration**

- Improve health, health care, health policy
- Accelerate implementation of evidence-based best practices for Dx, Tx, prevention, cure

- **Challenge**

- Understanding needs of patient population
- Communicating with end users of health care



The Citizen Scientist Program

Overview

- Bridge between community + researchers
- Lay perspective on research studies
- Leadership in OneFlorida, CTSI

Members

- 11 members
- Adults + Teens, 15- 80s
- Variety of cultural, ethnic, gender perspectives

Training

- Recruitment ongoing
- Training challenges + need
- Newer field



Case Study: Aspirin Study



- **National study**
 - Aspirin dosing
 - Older CV patients
- **Problems at UF**
 - Recruitment
 - Adherence to protocol

Content Creation

- **Initiation**
 - Set timeline, rough outline
 - Call in the experts!
- **Open Educational Resource**
 - New approach in clinical research, sharing of best practices
- **Instructional Design**
 - ADDIE model
 - Modified to ADDEI
- **ANALYSIS**
 - Interviews; video-based lessons

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Curriculum Modules + Lessons

Intro to Citizen Science (2)

Research Ethics (4)

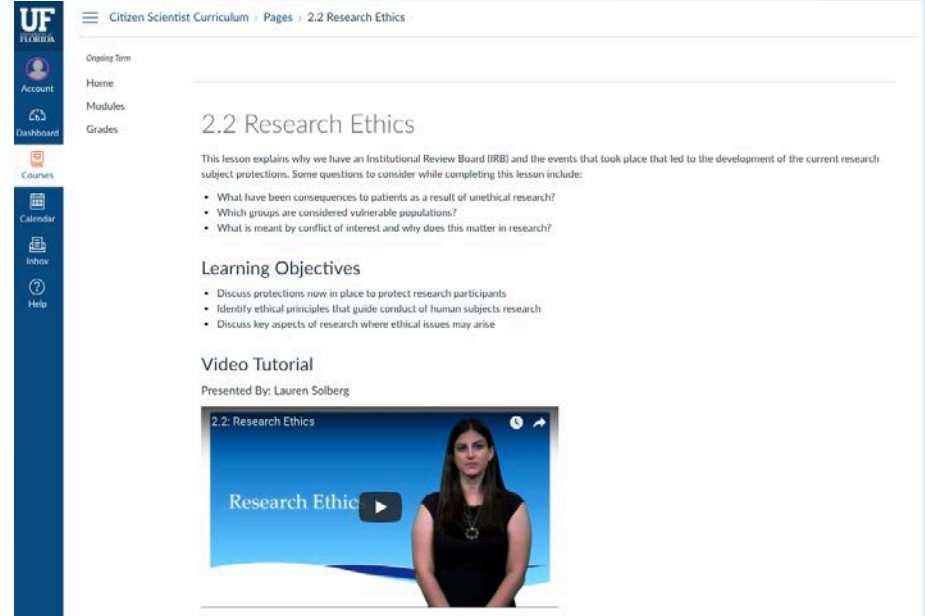
Sponsored Research (3)

Clinical and Translational Science (2)

Stakeholder Engagement (1)

Cultural Diversity in Research (1)

Biomedical Informatics (2)



The screenshot shows a web interface for the 'Citizen Scientist Curriculum'. The top navigation bar includes a hamburger menu, the text 'Citizen Scientist Curriculum', and a breadcrumb trail 'Pages > 2.2 Research Ethics'. On the left is a dark blue sidebar with the 'UF FLORIDA' logo and icons for 'Account', 'Dashboard', 'Courses', 'Calendar', 'Inbox', and 'Help'. The main content area has a white background. It features a '2.2 Research Ethics' section with a sub-header '2.2 Research Ethics'. Below this is a paragraph explaining the lesson's purpose and a bulleted list of questions to consider. The 'Learning Objectives' section follows, with a bulleted list of goals. At the bottom is a 'Video Tutorial' section, presented by Lauren Solberg, with a video player showing a woman in a black top against a blue background with the text 'Research Ethic' and a play button icon.

Citizen Scientist Curriculum > Pages > 2.2 Research Ethics

2.2 Research Ethics

This lesson explains 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. Some questions to consider while completing this lesson include:

- 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?

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 Tutorial

Presented By: Lauren Solberg

2.2: Research Ethics

Research Ethic

One of those “other” lessons



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- **EVALUATION**
 - Formative via group meetings, <60% correct, one complete revision

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- **IMPLEMENTATION**
 - Pilot test: Canvas, Two groups, July 2017- January 2018

A Tale of Two Groups

GROUP 1

- Existing CS members
- Ages: college- senior citizen
- Some experience in health care field (patients, one nurse)
- Diverse backgrounds (jobs, SES, ethnicity)
- N=6
 - 2 started but did not finish course
 - 1 finished course but did not complete Informed Consent

GROUP 2

- New CS members
- Ages: teenagers
- Some experience in health care field (patient only)
- Diverse backgrounds: (SES, ethnicity, geography)
- N=2

Total Assessment Scores:

Group 1 vs Group 2 First Attempts

Module Topic and Number of Assessments	Group 1 Total Module Score	Group 2 Total Module Score
Intro to Citizen Science (2)	93%	81%
Research Ethics (4)	82%	63%
Sponsored Research (3)	83%	73%
Clinical and Translational Science (2)	78%	68%
Stakeholder Engagement (1)	98%	95%
Cultural Diversity in Research (1)	77%	90%
Biomedical Informatics (2)	81%	83%

BMI and Big Data lesson:
73% vs 80%

Group score= Number correct responses for all members / number correct responses possible for all members

Citizen Scientist Curriculum: Evaluation

VIDEO

- Information easy to remember (62.5%)
- Easy to understand (75%)

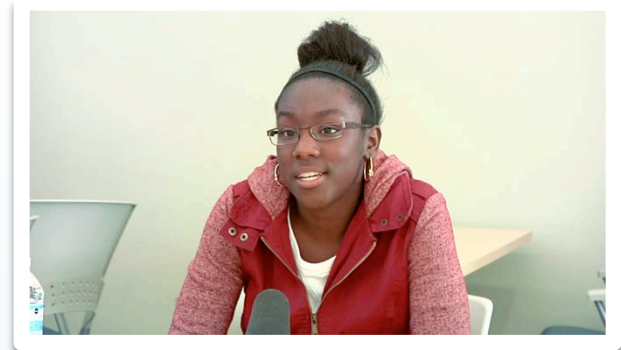
ASSESSMENT ITEMS

- Matched learning objectives (62.5%)
- Comprehensive (75%)
- Easy to understand 62.5%)

NARRATIVE

“The questions that I believe were the most helpful were the example based questions in the assessment. I believe that they were the best because they allow for us to apply the concepts to real situations, like we would in our job.”

“Much good and educational material covered and overall helpful”



Limitations and Lessons

- **Small Sample**
 - Descriptive statistics
 - Generalizability
- **Changes + Funding**
 - Future of the group
 - Summative evaluation
 - Usability testing
- **Why, then?**
 - Better feedback from CS
 - Certification for CS
- **Call in the experts, again**
 - Lock-step sequence
 - Required passing scores
- **End game follow-up**
 - How did CS feel afterward?
 - How did researchers react?
 - Anecdotal use immediately

Case Study: Aspirin Study, Revisited



- **Research team meeting**
 - Following a few FE sessions
 - Nine adult CS in attendance
 - UF Health CV team
- **Solutions from CS**
 - Rural NC Florida, spotty access
 - Enroll in CV office, randomize
 - iPads and practice facilitators

Acknowledgements

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COLLABORATORS

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For More Information:

bitly.com/cscurriculum

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THANK YOU



15 MILLION PATIENTS • 4,100 PHYSICIAN PROVIDERS • 1,240 PRACTICES/CLINICS • 22 HOSPITALS • 67 COUNTIES



Post- Session Evaluation

Please take 2 minutes to complete this brief but valuable post session evaluation. *Responses are anonymous and will be used to improve future programming.*

Type <https://bit.ly/scits2019> into your browser to launch survey

or

Scan this QR code



Thank you!

