

Enhancing the Mission of a Statewide CDRN through Citizen Scientist Education

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Background

- Stakeholder engagement is critical to the research process, yet many community stakeholders lack knowledge about clinical research.
- The OneFlorida Clinical Research Consortium, a Clinical Data Research Network (CDRN), utilizes Citizen Scientists to bridge the gap between researchers and community members.
- Citizen Scientists are integrated into all aspects of our CDRN but lacked an understanding of how research is conducted. This led to unrealistic expectations and frustration between researchers and Citizen Scientists.
- With help from Citizen Scientists and subject matter experts in topics ranging from research ethics to cultural competency, OneFlorida created a curriculum to better explain the research process to community stakeholders.
- The curriculum utilized best practices in the field of educational research including use of the ADDIE instructional design model, which incorporated Citizen Scientist feedback on content and design prior to implementation.
- Across the curriculum are 15 didactic lessons, each with a video presented by a subject matter expert and an assessment to gauge topic comprehension (Figure 1).

Methods

- An IRB-approved pilot study at the University of Florida examined assessment results and course evaluations for two groups:
 - Group 1: Existing Citizen Scientists (n=6)
 - Group 2: New Citizen Scientists (n=2)
- Content was loaded into the Canvas learning management system. This setup mirrored an online college course, with participants completing modules at home and then discussing the content with a program facilitator.
- Assessment scores were taken from each participant's first attempt, then analyzed by group. There was no limit on the number of retakes participants could attempt for each assessment. Course evaluation data was analyzed by both groups combined.
- It is important to note that Group 1 had encountered some of the curriculum content previously, either through the course of their role with the CDRN, or through the evaluation of curriculum materials as part of the content creation process.
- The analysis and dissemination of this study include a Citizen Scientist, who also helped evaluate and present the content as the curriculum was developed.

Results

- Group 1: The overall score across all modules was 84%, with scores ranging from 77% for the cultural competency module to 98% for the stakeholder engagement module. Total retakes: 35.
- Group 2: The overall score for this group was 74%, with the lowest score in the research ethics module (63%), and the highest in the stakeholder engagement module (95%). Total retakes: 22.
- Several differences in the scores between the two groups were observed, with group-specific results presented by module in Table 1.
 - Group 1, already familiar with most of the content, scored higher than Group 2 on most topics.
 - Group 2 scored noticeably higher on cultural competency, suggesting an existing awareness in previous education and/or practices of participants.
 - Group 2 had three of the 15 lessons (20%) with no retakes: Stakeholder Engagement, Cultural Competency, and Big Data in Health Care.
- Participants felt that the course was well designed, with 75% noting it was easy to understand information in the videos. Nearly 63% stated that assessment items matched the learning objectives, and 75% felt that the assessment items were comprehensive.



Module Topic	Lessons in Module	Group 1	Group 2
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 Competency	1	77%	90%
Biomedical Informatics	2	81%	83%

Table 1

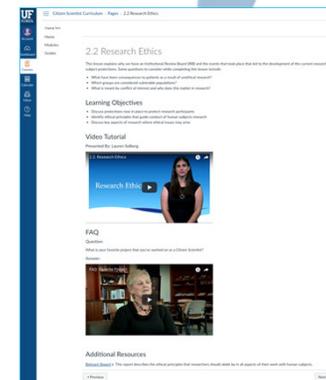


Figure 1

Conclusion

- Participants received certification and are using this knowledge to further the work done by OneFlorida.
- Suggestions by participants and a summative feedback will be incorporated into future implementations to the extent possible.
- Curriculum content and materials are available for other sites to use free-of-charge. This may help others improve the experience and quality of their patient engagement.
- The partnership with community stakeholders in science has proven to be an important strategy that can elicit direct, immediate benefits to research networks through improved recruitment strategies, reduced costs, and increased participation in studies.

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