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

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OneFlorida Clinical Research Consortium
University of Florida CTSI
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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  – Learning objectives, 7 modules: 15 didactic lessons, 15 other 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)**

15 MILLION PATIENTS • 4,100 PHYSICIAN PROVIDERS • 1,240 PRACTICES/CLINICS • 22 HOSPITALS • 67 COUNTIES
One of those “other” lessons
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  - 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

<table>
<thead>
<tr>
<th><strong>GROUP 1</strong></th>
<th><strong>GROUP 2</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Existing CS members</strong></td>
<td><strong>New CS members</strong></td>
</tr>
<tr>
<td><strong>Ages: college- senior citizen</strong></td>
<td><strong>Ages: teenagers</strong></td>
</tr>
<tr>
<td><strong>Some experience in health care field (patients, one nurse)</strong></td>
<td><strong>Some experience in health care field (patient only)</strong></td>
</tr>
<tr>
<td><strong>Diverse backgrounds (jobs, SES, ethnicity)</strong></td>
<td><strong>Diverse backgrounds: (SES, ethnicity, geography)</strong></td>
</tr>
<tr>
<td><strong>N=6</strong></td>
<td><strong>N=2</strong></td>
</tr>
<tr>
<td>- 2 started but did not finish course</td>
<td></td>
</tr>
<tr>
<td>- 1 finished course but did not complete Informed Consent</td>
<td></td>
</tr>
</tbody>
</table>
### Total Assessment Scores:

**Group 1 vs Group 2 First Attempts**

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

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

**BMI and Big Data lesson:** 73% vs 80%
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

**FUNDERS**
PCORI, NIH CTSA

**COLLABORATORS**
UF CTSI
Albert Ritzhaupt
Natercia Valle

**OneFlorida CITIZEN SCIENTISTS**
Anastasia Anderson, Shirley Bloodworth, Q Crawford, Christy Evans, Myrtle Graham, Claudia Harris, Nathan Hilton, Janelle Johnson, Bill Larsen, Carlos Maeztu, Nadine Zemon
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bitly.com/cscurriculum

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THANK YOU

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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....

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