

Co-Development and Usability Testing of Patient Engagement 101: A Patient-Oriented Research Curriculum in Child Health (PORCCH) E-Learning Module for Healthcare Professionals, Researchers, and Trainees

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Appendix 1, as supplied by the authors. Appendix to: Walsh CM, Jones NL, McCreath GA, et al. Codevelopment and usability testing of Patient Engagement 101: a Patient-Oriented Research Curriculum in Child Health e-learning module for health care professionals, researchers and trainees. *CMAJ Open* 2022. doi:10.9778/cmajo.20210336. Copyright © 2022 The Author(s) or their employer(s). To receive this resource in an accessible format, please contact us at cmajgroup@cmaj.ca.

Appendix 1A: Baseline Questionnaire

Baseline Questionnaire

1. You are a: ☐ Child ☐ Caregiver/parent ☐ Child health clinician
☐ Child health researcher ☐ Child health clinician researcher
☐ Child health clinical trainee ☐ Child health research trainee ☐ Other

2. Please describe your research field/discipline and/or clinical profession/specialty: _____

3. Age (if < 25 years old): _____

4. Sex: ☐ Male ☐ Female

5. Institution and/or City in which you live: _____

6. List the languages you are able to understand, speak, read and/or write. For each language rate your ability on a 1 (basic ability) to 5 (fluent) scale:

Language (please list)	Understanding (circle one)	Speaking (circle one)	Reading (circle one)	Write (circle one)
English	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

7. Please check your **highest** education level (or the approximate equivalent to a degree obtained in another country):

- ☐ Elementary school (specify grade: _____)
☐ Less than high school (specify grade: _____)
☐ High School
☐ Professional training
☐ Some college or university
☐ College
☐ University
☐ Masters
☐ MD, PhD, JD
☐ Other (please specify: _____)

8. Have you engaged in patient-oriented research previously? ☐ Yes ☐ No

If yes, please explain nature of engagement: _____

9. Please rate your knowledge regarding patient-oriented research:

- ☐ 1 (I don't know anything about patient-oriented research) ☐ 2 ☐ 3 ☐ 4 ☐ 5 (extremely knowledgeable)

10. Have you used e-learning before (online interactive learning?) ☐ Yes ☐ No

11. Please rate your comfort in using a computer:

☐ 1 (don't know how to use a computer) ☐ 2 ☐ 3 ☐ 4 ☐ 5 (extremely comfortable)

12. Please rate your comfort in using the internet:

☐ 1 (don't know how to use the internet) ☐ 2 ☐ 3 ☐ 4 ☐ 5 (extremely comfortable)

Confidence Questionnaire

Rate your degree of confidence by recording a number from 0 to 100 using the scale given below:

0	10	20	30	40	50	60	70	80	90	100
Cannot do at all					Moderately can do					Highly certain can do

	Confidence (0 – 100)
Patient Engagement 101, Part 1: Foundations of Patient Engagement	
1. I understand what patient-oriented child health research is	_____
2. I can describe some of the ways that patient engagement can lead to higher quality research	_____
3. I understand the values and goals of patient engagement in health research	_____
4. I am familiar with the key principles of meaningful and sustainable patient engagement	_____
5. I understand how to assess readiness for patient engagement among patients and families as well as researchers	_____
6. I am familiar with the spectrum of patient engagement and how the time and resources required for engagement increase along the spectrum	_____
Patient Engagement 101, Part 2: Patient Engagement in Practice	
1. I can describe some of the key elements of a patient engagement plan	_____
2. I can describe ways in which to engage patients and families at different stages of the research process	_____
3. I understand the importance of planning for patient engagement at the beginning of a research study	_____
4. I can describe some of the positive impacts that patient engagement can have for the research project, for the research team, and for partners	_____
5. I can describe some of the unique challenges of patient engagement and how they can be overcome	_____
6. I am familiar with the spectrum of patient engagement as well as various methods of engagement along the spectrum	_____

Knowledge Test

Patient Engagement 101, Part 1: Foundations of Patient Engagement

Please select the answer you believe is correct for each of the following statements.

- | | | | |
|----|---|------|-------|
| 1) | INVOLVE, PCORI, and SPOR are initiatives to promote patient engagement in health research | TRUE | FALSE |
| 2) | Patient engagement typically reduces the cost and resources required for a research project | TRUE | FALSE |
| 3) | Patient engagement helps focus research on topics of importance to patients | TRUE | FALSE |
| 4) | Key principles of patient engagement include inclusiveness, mutual respect, and co-production | TRUE | FALSE |
| 5) | Meaningful patient engagement includes research projects that involve patients but do not reflect their contributions | TRUE | FALSE |
| 6) | As the depth of patient engagement increases, more time and knowledge are required of both patient partners and researchers | TRUE | FALSE |

Match the following levels of patient engagement to the correct description:
a) consultation, b) involvement, c) collaboration.

- | | | |
|----|---|-------|
| 7) | Patient and families partner with researchers on all aspects of the research | _____ |
| 8) | Patients and families provide input on specific research issues via a focus group | _____ |
| 9) | Patients and families work directly with the research team throughout the project | _____ |

Knowledge Test

Patient Engagement 101, Part 2: Patient Engagement in Practice

Please select the answer you believe is correct for each of the following statements.

- | | | | |
|----|--|-------------|--------------|
| 1) | There are no definitive studies on the best patient engagement methods | TRUE | FALSE |
| 2) | Formal patient engagement plans are often unnecessary | TRUE | FALSE |
| 3) | Tools to evaluate important dimensions of patient engagement activities have not yet been developed | TRUE | FALSE |
| 4) | GRIPP2 is an example of a checklist to improve the reporting of patient and public involvement in research | TRUE | FALSE |
| 5) | Acknowledging the expertise of patients and families' lived experience is an important aspect of changing the research culture | TRUE | FALSE |
| 6) | Developing collaborative ways of working together helps avoid tokenism in patient engagement | TRUE | FALSE |
| 7) | Patients and families most often have the same motivations as researchers for engaging in health research | TRUE | FALSE |
| 8) | Multiple patient engagement methods from across the spectrum of patient engagement can be used within the same study | TRUE | FALSE |

POST-MODULE INTERVIEW

****You do not have to ask a question if it was addressed during module completion****

- Was the information provided in the modules helpful to you? **(Usefulness)**
 - *What did you find the most useful?*
 - *What did you find least useful?*
- Was there any information that you thought should be in the module but was not there? **(Gaps in information)**
 - *Is there anything you would suggest to add to the e-learning module to make it better?*
 - *Was there any information missing from the module?*
- How much did the module keep your attention as you were going through it? **(Engagement)**
 - *What parts did you pay the most attention to, and why?*
 - *What parts did you pay the least attention to, and why?*
- What parts of the module do you remember the most? **(Memorability)**
 - *What is the main thing you remember about the module?*
 - *What is the main thing you learned that stands out?*
- What parts of the module do you remember the least? **(Memorability)**
 - *Is there anything you are now more confused about?*
- Can you tell me what you liked best about the module? **(Satisfaction, Liked or disliked)**
 - *Information, layout, animations, graphics, etc.?*
 - *Can you tell more about that?*
- Can you tell me what you liked least about the module? **(Satisfaction, Liked or disliked)**
 - *Information, layout, animations, graphics etc.?*
 - *Can you tell more about that?*
- What did you think about the length of the module? **(Efficiency of use)**
 - *Do you think the module should be longer, shorter, or was it just right?*
 - *Why do you think so?*
- Can you tell me about how easy it was to navigate or find your way around the module? **(Learnability, Ease of use, Gaps in functionality)**
 - *What were the challenges of navigating through the module?*
 - *What would make it easier to navigate through the module?*
 - *What changes would make the module easier to use?*
 - *Were there sections of the e-learning module that you found particularly easy to use?*
 - *What about them made them easy to use?*
 - *Were there sections of the e-learning module that you found particularly hard to use?*
 - *What about them made them hard to use?*

- Can you tell me about what you thought about the overall look of the module? **(Aesthetics)**
 - *For example, the design, colours, and images in the module.*
 - *Does the module feel warm and friendly or cold and technical?*
 - *Can you tell me more about that?*
 - *Do you think it is visually appealing?*
 - *What would make the module more visually appealing?*
- Was the module easy to understand? **(Ease of understanding)**
 - *What did you find easy to understand?*
 - *What did you find difficult to understand?*
- Was the content easy to read? **(Aesthetics, Ease of understanding)**
 - *What did you think of the font?*
 - *What did you think of the amount of text?*
- Did the person talking present information too quickly, or too slowly, or was it just right? **(Ease of understanding)**
 - *What did you think about the pace of the module?*
 - *Were you able to understand what the speaker was saying?*
- Can you tell me what you thought about the information provided in the module? **(Information, Content, Learnability)**
 - *Was the information in the module clearly presented?*
 - *Was it easy to follow along with the audio and writing together?*
- What do you think about the amount of information that was provided? **(Gaps in information)**
 - *Was there too much information? Too little? Or was it just right?*
 - *How much of the information presented in the module did you already know before completing the module?*
- How do you feel about the accuracy of the information? **(Trustworthiness of information)**
 - *How much do you believe the information provided is true?*
 - *Is there anything you disagree with? Can you specify what/where?*
- If you could make changes to the module, what changes would you make? **(Would like to change/add)**
 - *Can you tell me more about that?*
 - *If you look through these slides (print copy) does anything come to mind?*
- What other things could help you to support what you learned through the module **(Gaps in information)**
 - *Do you think a handout would be helpful? A website? An app?*

- Overall, how satisfied were you with the modules? **(Subjective satisfaction)**
 - *Is there anything you would suggest changing to make the e-learning module better?*
- Can you tell me about whether or not you would use this module to learn more about patient-oriented child health research? **(Usefulness)**
 - *What section of the module would you refer back to, if any?*
- What would motivate you to use the module? **(Motivation)**
- Would you access this module from home if it was made available? **(Motivation)**
- Can you tell me about whether or not you think others would be interested in using this module? **(Usefulness)**
 - *Who would this be most useful for?*
 - *Would you recommend this module others? If so, who? Can you tell me more about that?*
- What would make it easier to motivate others to use the module? **(Motivation)**
 - *What would interest them in using this program?*
- Is there anything else you would like to tell us about the module? **(Other)**
 - *Can you tell me more about that?*

Appendix 1E: E-Learning Satisfaction Questionnaire

E-Learning Satisfaction Questionnaire

With regard to the E-Learning Education you just received, please indicate your level of agreement with each question below by marking a number between 1 (low agreement) and 5 (high agreement)

	Low agreement				High agreement
I learned something new	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
The information I received was easy to understand	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I received the right amount of information	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
My questions were answered	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
The goals of the session were clear	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
The length of time it took to finish the e-learning module was good	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
The e-learning module was easy to use	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

OVERALL

Please indicate your level of agreement with each question below by marking a number between 1 (not at all) and 5 (very)

	Not at all				Very
Overall, how SATISFIED were you with your education?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Overall, how ENJOYABLE was your education?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Appendix 1F: Additional Usability Feedback and Corresponding Module Changes

Topic	Quote	Corresponding Module Change(s)
Content		
Completeness: extent to which the module content contained all desired information	“I would also think that building these patient engagement activities into grants would be something to consider, especially when you think about compensation.” (P8, C1)	Added an additional suggestion for ways to address operational issues in authentic patient engagement: include engagement expenses in your budget and grant applications.
	“The other thing you can maybe add to this if you want another advantage of patient-oriented research is the enthusiasm you get from involving other people.” (P15, C1)	Added “increased enthusiasm for the research” as another value-add of partnering with patients and families in child health research.
Relevance: the relevance of the module to its intended users	“It’s funny, I’m surprised the module is so alive with my own experience.” (P4, C1)	
	“This [Assessing readiness for patient engagement] section [...] has both the family’s point of view and the researcher’s point of view [...], so if patients look through the module, they see your point of view, and if you look through the module, you see their point of view—I find it very helpful.” (P13, C1)	
Learner Experience		
Preference for information access: users’ preferences regarding information access	“If there was an additional resource that was in the module, but I didn’t save it, could I just go back to the website to find it quickly without going back into the module?” (P4, C1)	Added a table containing all additional resources files for Patient Engagement 101 on the PORCCH website.
Design Aesthetic		
Features: interactive elements of the module	“This one has tick boxes. Can you click more than one?” (P14, C1)	Added an explicit “select all that apply” instruction for the checkbox-style knowledge check questions.
Layout: the arrangement of text and graphics on slides	“The ‘select your answer’ prompt is pointing towards the [true response]—it’s kind of guiding respondents.” (P10, C1)	Ensured that all prompts on the true or false knowledge check questions were neutrally positioned.
Navigation: the ability of the user to easily move around the module	I like how it links me back to that main page, like now you’re done with that [section] so now you’re moving onto the next one.” (P28, C2)	

Abbreviations: P: Participant; C: usability cycle.