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Title: 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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REVIEWER 1 and author response
Anna Rychtera

1) I would like to see a plan for evaluation over longer time period, what are the long-term effects?
   - Thank you for the feedback. In this co-development and usability testing study, we were only able to collect immediate self-report measures around knowledge and self-efficacy/confidence to engage in patient-oriented research. As we note in the Discussion (page 16, lines 547-549), *"It would be useful to evaluate longer-term outcomes, such as whether completion of Patient Engagement 101 is associated with greater engagement of patients and families in research."* In the future, we hope to conduct a study of users that have registered and completed the modules that are openly accessible on www.porcch.ca, in an effort to elucidate long-term effects of the curriculum. Ideally, this question would be addressed through a prospective study with randomization and an active control, so as to overcome (self-)selection biases.

2) Would like to see more than 1 PP (patient partner) on research team and PP should be mentioned as co-researchers.
   - Thank you for your comment. One of the module co-leads was a parent partner, and we have revised the Methods to articulate the membership of the steering committee more clearly, which included 3 parent partners (page 9, lines 297-299). We have also operationalized the level of engagement in the study per a widely used framework (page 6, lines 186-189): *"The module was co-developed through a sharing of power and responsibility across all phases between clinicians, researchers, and patients and families, in accordance with what the International Association for Public Participation (IAP2) defines as collaboration.[15]"* In concert with the changes above, we think the stakeholder- (parents) and role- (module co-lead, steering committee member) specific terminology in the manuscript are preferable over describing all parents on the research team as (parent) co-researchers in striving for proper recognition of 'non-professional' research team members and their contributions as well as clarity in describing the methods of engagement in the study. In reflecting on your comment, we have designated the parent module co-lead (FB) as a co-senior author in recognition of their contributions, and we have made this change (page 1, lines 6-9).

3) Missing a plan for knowledge translation and make sure PP are involved actively in KT
   - Thank you for your comment. A multi-faceted KT plan has been developed by the PORCCH steering committee, led by two knowledge translation experts and three parent partners. The initial focus of the KT strategy has been dissemination of the PORCCH curriculum locally, nationally, and internationally by raising awareness through email and social media, providing site access, and reaching out to key stakeholder groups. The goal of the KT strategy is to build capacity in patient-oriented research in child health. The KT plan is not discussed in this paper, as the KT plan pertains to the PORCCH curriculum as a whole, whereas the focus of this manuscript is on the co-development and usability testing of the 'Patient Engagement 101' module specifically for healthcare professionals, researchers, trainees, and other interested

stakeholders. Some details on the KT strategy for PORCCH are available in another paper - Macarthur C, Walsh C, Buchanan F, et al. Development of the patient-oriented research curriculum in child health (PORCCH). Res Involv Engagem. 2021;7(1):27) - which is cited in the Introduction and Discussion of this manuscript. The steering committee (including parent partners) and the parent partner co-lead of the Patient Engagement 101' module (FB) are actively involved in implementing the PORCCH KT plan.

REVIEWER 2 and author response
Soo Chan Carusone / Casey House

1) It would be helpful to provide some more details about how people were recruited to participate in the testing. For example, was it through personal networks of team members, open invitations through email lists? It seems that there was a relatively high experience-level with patient-engaged research. My understanding is this is somewhat different from the target audience of the module. If this is correct, I think it is important to acknowledge the implications of this. It may also be valuable to acknowledge that because of the recruitment approach (and volunteer nature of participation in this research study) that these participants may be particularly motivated and positive about the module.
   - Thank you for your comment. We've revised the Methods (page 7, line 220) to specify that participants were recruited *"through study advertisements distributed via newsletters and email lists."* In our sampling, we purposively sought to recruit participants with and without previous patient-oriented research experience, as we thought both perspectives would be informative for usability testing. As indicated in Table 1, two-thirds of participants had experience with patient- oriented research already, which, as you highlight, may represent more experience than the typical user of the module. We've mentioned in the Limitations (page 16, lines 543-545) that *"Participants, who were recruited through pediatric research and family advisory networks for their familiarity with patient-oriented research, may not fully represent the intended end users of Patient Engagement 101."*

2) You state that "a purposive sample of end-users was recruited to achieve maximal variation in the testing group, particularly with respect to participants' clinical and patient engagement in research experience." Can you elaborate on what you mean? It appears that you strove for one caregiver and one patient in each round – how else did you seek "maximal variation"? And, if more than the target number volunteered in a category, how did you choose which ones to invite?
   - Thank you for your questions. Maximum variation is a purposive sampling method in which specific variables to sample along are identified *a priori*. We have revised this section of the Methods for clarity (page 7, lines 224-228): *"A maximal variation purposive sampling approach was employed to ensure diversity in the testing group, particularly with respect to participants' role (i.e., researcher, clinician-researcher, patient, caregiver), patient engagement in research experience, and geographic location.[21,22] Researchers and clinician-researchers, the module's target audience, were predominantly sampled."* We recruited the first eligible participants to express interest in response to the study advertisements.

3) It would be helpful to report on how the knowledge and self-efficacy questionnaires were developed and if they were pilot tested with external members to assess the relevance of the concepts assessed.
   - Thank you for the comment. The content for these questionnaires was generated from the literature review conducted to collate content for the module. As we describe in the Methods (pages 7, lines 232-254), the confidence (formerly self-efficacy; please see next comment)

questionnaire was developed based on Bandura's framework for constructing self-efficacy scales, and the multiple-choice knowledge test was designed to target assessment of the "knows how" level of Miller's framework for assessing levels of clinical competence (i.e., interpretation, application of knowledge). We had removed details of pilot-testing from our original submission due to word limit restrictions but have added this back into the Methods (page 8, lines 255-256): *"these questionnaires were pilot-tested by three child health researchers/clinician-researchers to verify clarity and content validity."*

4) My primary concern with this paper is the self-efficacy questionnaire seems to assess more knowledge than self-efficacy. Self-efficacy tools should be assessing someone's self assessed ability/confidence in being able to "do" something while many of the items on the survey (and the opening sentence of the tool) refer to "understand"ing. While having basic knowledge and understanding about what patient-oriented research is and key steps in properly operationalizing it, is an important first step in being able to DO patient-oriented research I do not think this should be referred to as "self-efficacy".
   - Thank you for your comment. We agree with the points you made. In line with this comment, we have changed the term used to describe the underlying construct of the questionnaire from self-efficacy to confidence throughout the manuscript.

5) You do not state what your hypotheses were a priori, but I assume self-reported knowledge was an important outcome you hypothesized the module would positively impact. I think the fact that this measure did not demonstrate significant change should be included in the abstract (given the reporting of the other outcomes) and receive more consideration. On page 21, you explain that this finding is "indicating participants likely have unperceived needs related to patient-oriented research which Patient Engagement 101 addressed." I agree that this may be true, but it may also be true that your knowledge test does not capture information/domains perceived to be important.
   - Thank you for your comment. We have revised the Discussion to add that the discrepant results across the knowledge test and self-rating may be due to the former not capturing all relevant domains (page 15, lines 517-520) as follows: "*Interestingly, while participants' knowledge test scores increased after module completion, their self-reported knowledge did not, indicating that the knowledge test may not have captured all relevant domains or that participants have unperceived needs related to patient-oriented research*.[43]" We have also revised the Abstract (page 3, lines 91-93) accordingly: *"Significant increases in participants' knowledge test scores and confidence to engage in patient-oriented research, but not self-rated knowledge, were observed after module completion."*

6) Other comments: I believe in the demographic survey "gender" (vs sex) would be a more relevant variable to capture.
   - Thank you for the helpful comment. We agree that in retrospect inquiring about gender, the social construct, versus sex, the set of biological attributes, would have held greater relevance to our study and we will incorporate this in our future work. The demographic table (Table 1) presents the same terminology (i.e., "sex," "male," "female") that participants responded to on the demographic form (Appendix 1). Unfortunately, it is not feasible for us to re-contact participants to inquire about their gender identity. In the spirits of respecting participant autonomy and distinguishing between sex and gender in health research, we think it makes the most sense to report these data as they were originally captured.

7) Page 15 – typo “Paired t-tests were used” not “using”
   - Thank you for catching this and letting us know; we have made the correction.

8) Table 1: Does “education level” “college/university” refer to some or completed college or university for their highest level of education attained?
   - Thank you for your comment. It refers to “highest education level completed,” and for clarity we have rephrased the variable in Table 1 in this manner.

REVIEWER 3 and author response
Rich Sobel /patient partner reviewer
As the "patient partner" reviewer, I'd like to especially commend the authors on the readability of this article. It once again proves that you don't need a whole bunch of fancy jargon to describe an important research study.

This paper is timely in that, as they mention, many such efforts are ongoing both in Canada and globally to produce materials and raise the awareness of CIHR's SPOR and awaken both the researchers and patients/caregivers to this new way of conducting health research. While the title of the paper seems to indicate that the modules are aimed at decision-makers, researchers and trainees, the modules also work quite nicely for introducing the patient partner component of SPOR to their roles in being part of a research team.

I also liked how in the tables, quotes were included that showed where certain barriers were encountered by the testers and how they were addressed. I look forward to seeing how many more "hits" this program gets and future modifications as a result.

1) I did notice that for whatever reason, your testing population was essentially female. In the future, you need to remedy that and show much greater diversity. Also, you may want to consider populations that are currently excluded due to barriers that include sight, hearing, language, etc. I'm sure you're already thinking about that, but a reminder never hurts.
   - Thank you for the helpful comments. We agree and acknowledge that our study would have been strengthened by a more diverse group of usability testers. We have added discussion around this important issue to the Limitations: (page 16, lines 543-551): *“Participants, who were recruited through pediatric research and family advisory networks for their familiarity with patient-oriented research, may not fully represent the intended end users of Patient Engagement 101 [...] It would be useful to evaluate longer-term outcomes, such as whether completion of Patient Engagement 101 is associated with greater engagement of patients and families in research, in a larger and more representative sample that reflects the diversity (e.g., education, ethnicity, gender identity, persons with disabilities) of those involved in patient- oriented research.”*