



Patient Engagement In Research Scale (PEIRS) Study

Clayton Hamilton^{1,2}, Alison Hoens^{1,2,3}, Kelly English³, Annette McKinnon³, Shanon McQuitty³, Linda Li^{1,2}
¹University of British Columbia, ²Arthritis Research Canada (ARC), and ³ARC- Arthritis Patient Advisory Board



INTRODUCTION

Patients who engage in research (i.e. patient partners) undertake roles beyond that of study participants, in conducting activities and making decisions at any stage of health research, from inception through impact evaluation.

The perspectives of patient partners can enrich the quality, relevance, and impact of research. In Canada, interventions such as researcher training workshops are being developed to optimize patient engagement in research.

There is, however, a lack of validated measurement tools to evaluate *meaningful* patient engagement in research to test the effectiveness of interventions to improve the quality and mechanisms of patients engagement in research.

PURPOSE

To develop and validate a novel outcome measure, the Patient Engagement In Research Scale (PEIRS), for evaluating the degree of *meaningful* patient engagement in health research from a patient partner perspective.

The PEIRS is to be completed by patient partners before and after an intervention is implemented, to test the intervention's effectiveness in promoting meaningful patient engagement in research. Using the PEIRS to improve patients engage in research could advance how patients' perspectives lead to improve the quality and impact of health research.

This project will significantly contribute to the knowledge base of patient engagement in research.

AIMS

PHASE 1
To create a set of items that reflects the elements of patient partners' perspectives on meaningful engagement in research.

PHASE 2
To develop the PEIRS using the most relevant elements of *meaningful* patient engagement in research.

PHASE 3
To evaluate the validity and reliability of PEIRS.

METHODS

Study Design: Mix of qualitative and quantitative methods

Sample: All participants will be patient partners (patients or their surrogates) who are communicate in English.

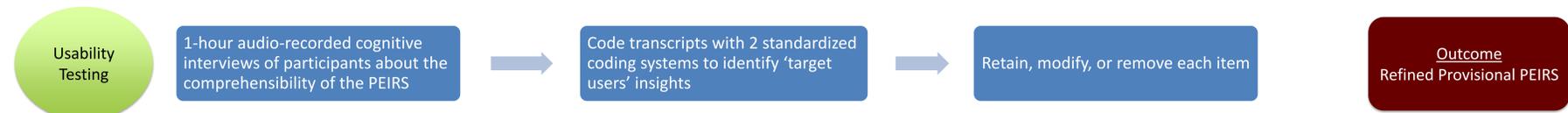
PHASE 1 – Creation of Items

- Sample: 18 transcripts from a qualitative study which explored patients' views and experiences of engaging in research



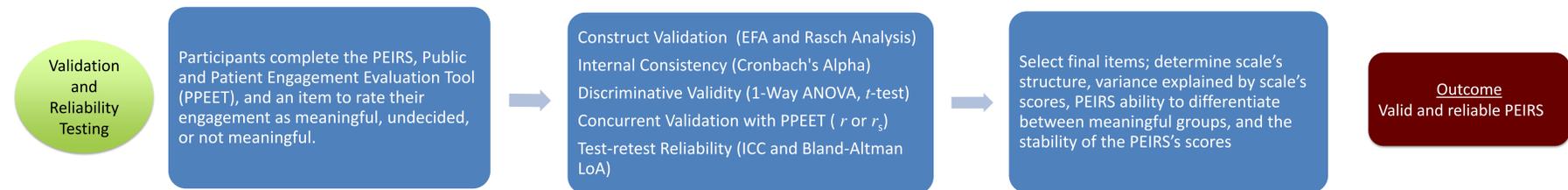
PHASE 2 – Item Selection and Usability Testing

- Sample: Two purposive samples of 12 participants each will be recruited, one for a 3-Round Delphi process and one for usability testing



PHASE 3 – Validation and Reliability Testing

- Sample: 100 patient partners across a variety of health issues who have experience partnering in research in Canada. Eligible participants will be those who engaged in research during the last two years.



KNOWLEDGE TRANSLATION

This research uses an integrated knowledge translation (iKT) approach, having a strong partnership between experienced patient partners and researchers who co-designed this study to ensure the relevance of the PEIRS to patient partners. We are collaborating at every stage, and will co-lead KT activities to promote the PEIRS to knowledge users (patients, researchers, research organizations). Findings will be published and presented at educational sessions. A website will host the PEIRS and provide updates on its use.

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a place of mind

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