“Lost in time”: Updating the content and clinical accessibility of the Prosthetic Upper Limb Functional Index (the PUFI-2)

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Background

• The original Prosthetic Upper Limb Functional Index (PUFI) is a validated computer-based clinician administered questionnaire completed by children and/or their parents
• It was created and validated over 25 years ago here at Holland Bloorview
• The PUFIs evaluates a child’s prosthetic use in a range of daily bimanual activities
• In the last decade, the PUFIs clinical use declined due to outdated content and software incompatibility
• We have recently updated the PUFIs and renamed it the PUFI-2
• Parents and children from Holland Bloorview and occupational therapists (OTs) in international pediatric clinics were involved in this updating via completion of two web based PUFIs item generation/reduction surveys

Objectives

1. To learn about the experiences, perceptions and interpretations of children and/or their parents in completing the new PUFI-2 that is accessed on-line in REDCap (a secure web based portal)
2. To determine if further revisions to PUFI-2 content and format are required, and to help inform clinical administration guidelines.

Methods

• Mixed methods study: A clinical utility survey and one-on-one cognitive interview via zoom were conducted with children and parents as part of a PUFI-2 completion experience
• Topics addressed: Comprehensibility, clarity of instructions, suitability of response scales, ease of completion, visual appeal, time to completion, further development
• Quantitative and qualitative data were collected concurrently, analyzed separately, then merged

Results

1. Study sample: 3 parents of younger children, 2 parents of older children, and 3 older children from the Prosthetic Service at Holland Bloorview
2. Two main themes with subthemes emerged from the interviews. Results from the clinical utility survey were consistent with the interview themes.
   • Theme 1: Enablers/facilitators of PUFI-2 administration
   - Real-world pictures of kids are helpful in answering questions
   - Comprehensive age appropriate activities are represented
   - User friendly format and interface
   - Computer, laptop or tablet with large screen would be the preferred device with option of completing the PUFI-2 at home or in clinic
   • Theme 2: Factors affecting response accuracy
   - Inconsistent use of response guide
   - Need for clarity of response options and terminology
   - Item and question composition

Discussion and Recommended Changes

Involvement of children and parents in evaluating the PUFI-2’s content and format brought forward reality-grounded ideas from users’ perspectives on changes needed to improve the PUFI-2’s usability, response accuracy and uptake.

1. Create a PUFI-2 intro video clarifying the variety of performance methods and offer user friendly terminology.
2. Emphasize key words in questions e.g., “How do you usually do the activity?”
3. Include response option e.g., “Never tried the activity/assemble think what would perform look like if attempted”.
4. Simplify broad activity items
5. Add “Other” comment box
6. PUFI-2 completion via large screen device (computer/tablet/laptop) at home or in clinic.
7. Brain breaks or “half way to go” prompts

Factors affecting PUFI-2 response accuracy

“I don’t know what actively means.” (Youth)
“Unzip and remove a heavy book or a laptop.” “Open a zipper pouch.” “I guess there’s two things, to open the zipper and to also remove the item. So there’s two things plus there’s three options you’re describing, it’s very busy […] But I think the taking out part is important because she does use it to help her get the stuff out”. (Parent)

“I thought it was good for giving people who are administering it evidence of how the children accomplish the activities. It was easy to see from the pictures what the activity was and the questions were detailed enough to find out how they use their prosthetics”. (Parent)

“Quite thorough in terms of the activities included and getting information from the children about how they use their prosthetic”. (Parent)

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Next steps

• Feasibility testing with international partners
• Implementation pathway design tailored to each clinic setting
• Further revisions to improve clarity of response options, terminology and item composition and photo representations
• Language translations (as we did with the previous PUFI)
• Re-validation study
• Development of a PUFI-2 web app that is accessible to clinicians in hospitals, private clinics and research facilities

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