# "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 PUFI evaluates a child's prosthesis use in a range of daily bimanual activities
- In the last decade, the PUFI's clinical use declined due to outdated content and software incompatibility
- We have recently updated the PUFI 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 PUFI 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

- **Study sample:** 3 parents of younger children, 2 parents of older children, and 3 older children from the Prosthetic Service at Holland Bloorview
- 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

# Enablers of PUFI-2 administration

"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 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)

"I'm speaking with 8 years of experience with prosthetics…I'm very actively involved in the decisions for my daughter's arms… I would prefer to do it before I got there. One of the things from looking at it is the timing of appointments and trying to make the most of your time so if you were telling someone their appointment is at 1 but you need to come at 12:30 so you can fill out this form, I think that would be a turn-off. I would do it at home within a week of my appointment." (Parent)

# 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 zippered 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)

"If there was an option saying -could you imagine doing this with your prosthesis on how would it go?... If I were to imagine then yes she probably could do it." (Parent)

"*Can't do the activity even with help* - I wouldn't put that one because I've done it before without help but I just don't usually do the activity. And *no never needs to do the activity* - I sometimes do the activity, and I'm obviously not too young to do it because I've done it before." (Youth)

Please scan the QR code to learn more about our current PUFI-2 research

## PUFI-2 Visual Appearance and Sample Photos
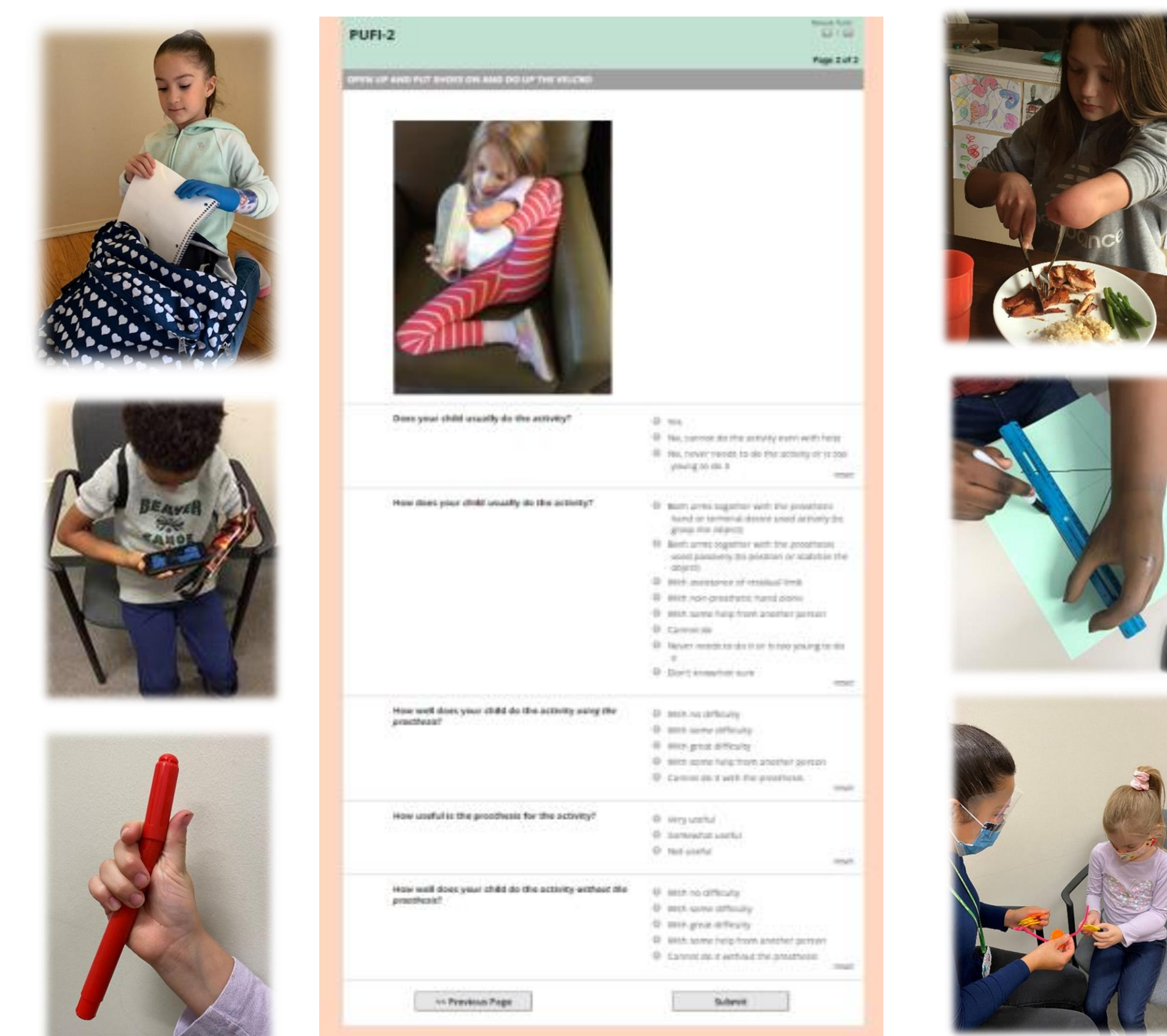


## Discussion and Recommended Changes

**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/**imagine** what would performance 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

## 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

## Funding