

# **Aligning Independent Decisions (A.I.D.) for Appearance: Alpha Testing of a Patient Decision Aid for Cleft Revision Procedures**

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## **Background and Hypothesis:**

Cleft lip and/or palate is the most common craniofacial anomaly worldwide, affecting 1 in 700 births. Individuals typically undergo multiple surgeries, with some choosing elective cleft revision later in childhood to improve appearance. To support patients in this process, an online patient decision aid was developed to provide surgical information, outline benefits and risks, and help identify personal values. We hypothesized that during alpha testing, this decision aid will be viewed as acceptable, appealing, and user-friendly by participants.

## **Project Methods:**

After IRB approval, participants not actively facing a cleft revision decision were recruited by phone for alpha testing: 4 craniofacial surgeons, 7 parents of children with cleft lip, and 2 children with isolated cleft palate. Participants viewed the decision aid using a “think aloud” approach, and sessions were recorded and transcribed. Codes were developed through content analysis, and themes evolved with code review. Participants also completed the Decision Aid Acceptability questionnaire and the System Usability Scale (SUS).

## **Results:**

Thirteen participants completed alpha testing. Parents rated the decision aid highest for usability (Mean system usability scale score) = 93.2), followed by surgeons (78.8) and children (70.0). Most participants (76%) reported the tool’s length and information were “just right” and perceived its tone as balanced. Nearly all (92%) indicated the decision aid would be helpful for surgical decision-making. Qualitative analysis identified key themes of use of affirming language, supporting realistic expectations, and improving decision aid navigation and usability.

## **Conclusion and Potential Impact:**

The current decision aid will be adapted based upon both quantitative and qualitative analysis from alpha testing. Improving access and usability may enhance shared decision-making, reduce conflict, and increase confidence in cleft revision decisions. The updated version will undergo beta testing with patients actively considering cleft revision surgery, and the final decision aid will serve to facilitate patient-centered decision-making in a highly preference-sensitive clinical situation.

