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Consensus Panel for Assessing Usability and Acceptability of Mobile Health Autism Screeners

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Mobile health, screening tools, recommendations

Abstract

Introduction

Parents and healthcare providers who have developmental concerns about a child may use autism screening tools online. Online screening tools may improve autism screening though advanced technologies and improved connection to services. However, language, cultural, and technological barriers may impede equitable access to care.

Objective

Create consensus recommendations for equitable design of autism screening apps and websites

Methods

We used consensus methodology to develop recommendations for improved online autism screening tool design. 3 pediatricians, 2 tool developers, 3 early intervention providers, 3 autistic adults, and 4 parents participated in a Modified Delphi panel. The panel included 3 asynchronous rounds of online discussion and voting using Slack, and one live online videoconference. Participants received a multimedia summary (written summaries, videos, interactive polls) of research on screening tool usability/accessibility, and a list of 28 preliminary design recommendations from our prior research. Each round, participants provided commentary on combining or altering wording of recommendations, suggested alternative or additional recommendations, and voted for up to 10 recommendations. The recommendation list was iteratively revised and reduced. In the final round, recommendations were grouped into categories. A final consensus guideline was developed based on the vetted recommendations.

Results

The consensus panel produced 19 final recommendations (Table 1), in 5 conceptual categories: transparency, equity, access, product design and user experience, and development process. Recommendations receiving the most panelist votes overall at the end of the panel process were: "tools should directly link to sources of information about autism and/or community resources", and "tool reading level should be 5th grade or less and should be easily understandable for parents with elementary level math education."

Conclusion

A multidisciplinary panel can translate research findings to actionable recommendations for equitable autism screening. Direct input from individuals impacted by current autism screening guidelines can help create guidelines that reflect stakeholder experience.

Table 1. *Final recommendations for mobile online ASD screening tools from consensus panel*

Group 1: Transparency	
1.	Tool should not include links to advertisements for commercial products or services
2.	Tool should clearly explain its objective(s) on the first screen
3.	Tool should request the minimal level of personal data needed to function as a screener and be transparent about how it uses child/parent data
Group 2: Equity	
4.	Tool should explain what autism is, include positive characteristics of children with autism, and incorporate the perspectives of autistic people in information provided to families
5.	Tool should directly link to sources of information about autism and/or community resources, and should allow parents to directly refer the child to local child development programs (e.g. Early Intervention)
6.	Tool should have gender, racial/ethnic, and cultural diversity in videos, questions, and graphics ; should show humility with respect to minority individuals and cultures
7.	Tool reading level should be 5th grade or less; should be easily understandable for parents with elementary level math education
8.	Fees (costs) to the family should be apparent up-front
Group 3: Access	
9.	Tool should specify a child age range that it targets
10.	Tool should be accessible on multiple mobile platforms (e.g., iOS, Android) and should be version-compatible with older and less expensive devices
11.	Parents should be able to complete the tool on average in <10 minutes; Trained personnel should be able to interpret the tool on average in <5 minutes
Group 4: Product Design and User Experience	
12.	Tool should avoid stigmatizing words (e.g. "normal," "abnormal," "risk")
13.	Tool should provide user support resources (e.g., help when you get stuck or are confused)
14.	Tool should not associate red color, bolding, or other stressful signals with a positive test result
Group 5: Development Process	
15.	Tool's test properties (i.e., accuracy) should be studied in the under-resourced communities and common languages in the countries in which it is marketed
16.	Tools should be developed for the wide range and variability of behaviors, needs, strengths, and individual experiences associated with autism, including both children with high support needs and children with subtle, atypical, or inconsistent behaviors and presentation
17.	Tools should be developed, tested, and made available in the most common languages in the countries in which they are marketed
18.	Funders should explicitly request that new mHealth autism screeners include equity considerations and provide funding for this purpose
19.	Tool design should be participatory and include both parents and autistic individuals