**Title**: User Experience and Acceptability of the Parent-Assisted Neurodevelopmental Assessment Box (PANDABox) Tool

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**Introduction**: For parents of children with neurodevelopmental disorders (NDDs, e.g. Down syndrome), the clinical assessment, while necessary, is often a source of stress. Many existing assessments are often not sensitive enough to measure the abilities of a child with developmental disabilities, particularly as they change over time. The PANDABox (Parent-Assisted Neurodevelopmental Assessment; Kelleher et al., 2020b) is a standardized protocol for collecting laboratory-grade behavioral and psychophysiological data remotely, without a technician on-site. PANDABox was designed to be accessible to children with a variety of neurodevelopmental conditions that require frequent surveillance, including children with neurogenetic conditions typically characterized by developmental delays and sensorimotor impairments. An initial publication applying the PANDABox approach to a small cohort of children with Down syndrome indicated that PANDABox is highly feasible and acceptable to caregivers (Kelleher et al., 2020a). Here, we examined PANDABox performance in a broader cohort of participants with Angelman syndrome, Down syndrome, fragile X syndrome, and typical development. Specifically, we examined caregiver-rated acceptability of the PANDABox experience across three domains: Process, Technical Factors, and Assessment. Our research questions were: [1] Do at least 80% of participants exhibit “positive” scores—where average score is “good” or greater—across each domain (Process, Technical, Assessment)? [2] Are there specific gaps in the protocol, as indicated by poor ratings on any specific acceptability items? [3] Do average acceptability scores across each domain differ between syndrome groups?

**Method**: Following the completion of their first telehealth assessment, parent participants were encouraged to report their experience with PANDABox using a brief, anonymous survey—72 participants with children diagnosed with Angelman syndrome (n = 16), Down syndrome (n = 21), and fragile X syndrome (n = 11), as well as nonsyndromic controls (n = 24), completed this survey. Respondents rated their satisfaction on 16 items using a Likert scale (1-Poor, 2-Fair, 3-Good, 4-Excellent); these questions have been grouped into three domains: Process (e.g., clarity of instructions, interactions with research team), Technical (e.g., telehealth visual quality, length of time), and Assessment (e.g. personal comfort with the assessment, assessment’s ability to capture child’s abilities). Preliminary psychometric testing indicated that these items have high internal consistency and content validity for measuring acceptability among neurodevelopmental disorder caregiver populations.

**Results:** For question 1, descriptive analyses indicated that we exceeded our threshold; at least 94% of participants’ scores were “good” or greater in each domain (Process = 98.6%, Technical = 94.4%, Assessment = 94.4%). For question 2, positive responses across all 16 items also reached our pre-set threshold, varying from 90.2-100% positive. To address research question 3, we performed a one-way ANOVA to compare the effect of syndrome group on acceptability scores for each of the three domains. Results indicated a statistically significant difference in mean score between groups for the Technical domain (p = .005), while the Process domain approached significance (p = 0.063). The Assessment domain was not significant (p = .735). We then used two-sample t-tests to compare each syndrome group across both the Process and Technical domains respectively. Results indicated that when compared to controls, each syndromic group had significantly higher Process and Technical scores (p’s < .05). Angelman syndrome caregivers also reported significantly lower Process scores compared to fragile X caregivers (p = .037).

**Discussion:** Remote assessments offer promise for easing clinical access for rare disorder families, however procedures must first be shown to be acceptable to caregiver users. Our findings suggest that PANDABox is an acceptable tool for remotely assessing children with NDDs, potentially providing an accessible alternative to traditional in-person assessments. Caregiver satisfaction was robust across surveyed domains and tasks and achieved our pre-set threshold across all syndromic and non-syndromic groups. Now that PANDABox has been shown to be acceptable, a next step will be to examine the clinical utility of PANDABox-collected data in improving phenotypic information about neurogenetic conditions.

**References:**

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