The Power of Crowdsourcing for Patient Engagement in Clinical Studies  
C. Lajonchere and B. Vaughan, Cognoa, Inc., Palo Alto, CA

ABSTRACT: 
Background: Increased use of mobile platforms for healthcare delivery can be effective in providing improved access to care, especially for low income and minority populations who face greater healthcare disparities. Crowdsourced health research studies are emerging across the healthcare sector as a complement to the more traditional research studies. However, clinicians and researchers are still concerned about the accuracy of parent-reported outcomes. Small samples and noncompliance continue to serve as barriers for the more traditional clinical trials. Cognoa’s evidence-based mobile tools leverage the use of big data and machine learning to give parents and providers an estimate of a child’s risk for a developmental delay based on information that parents collect from the privacy of their homes. For a company like Cognoa that engages large numbers of parents, crowdsourcing offers a myriad of opportunities to reduce those barriers and push the limits of research participation and data collection.

OBJECTIVES: To determine the response rate of parents who provided clinical outcome data 3-6 months after completing the mobile questionnaire and to compare the distribution of diagnoses across different risk categories and age cohorts.

METHODS: Cognoa sent emails to parents of children 18mo-5 years of age, 3-6 months after they received their Cognoa results to determine whether they had followed up with a provider. Parents were asked to indicate the type of provider, if any, who provided a diagnosis. Parents were able to select from a variety of diagnoses as well as provide their own. The algorithm classified children as elevated, medium or low risk across 3 age cohorts: <36 months, 3-5 yrs, 6+ years.

RESULTS: Over a period of 6 months, 2,927 parents responded to the email campaign. Seventy-two percent (72%) of respondents said that they had either received the all clear from their doctor (38%) or hadn’t yet followed up. Fifty-three percent (53%) of those that hadn’t followed up were parents of children in the low risk category. Of the 819 parents who received a formal diagnosis, forty-nine percent (49%) indicated that a medical doctor had provided the diagnosis, 29% reported that a clinical psychologist had diagnosed, and the remainder was comprised of other providers. The algorithm classified 44% at low risk of a developmental delay, 27% as medium risk, and 29% as elevated risk. On average, children in the elevated risk category had a statistically greater number of co-morbid diagnoses (p<.05) than those in the other risk groups. Young children <36 months did not exhibit a significantly different number of diagnoses across risk categories. However, as children got older, the diagnostic complexity of children in the medium and elevated risk groups began to emerge (p<.05).

CONCLUSIONS: These results indicate that mobile crowdsourcing can serve as an important mechanism to reach a broad reach of individuals than can be done in more traditional clinical trials. This mechanism has the opportunity to reach a more diverse population, especially those
individuals with the greatest health disparities. This study served as another mechanism to validate Cognoa’s evidence based algorithm in a real-world setting.