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Barriers and Facilitators to Precision Medicine for Black Children with Autism Spectrum Disorder

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Barriers and Facilitators to Pharmacogenetic Testing In Black Children with Autism Spectrum Disorder

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Background & Objectives

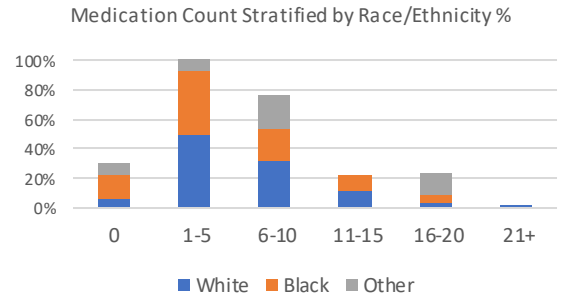
- Children with autism spectrum disorder (ASD) are more likely to be diagnosed with co-occurring mental health disorders and are also at increased risk for poor clinical response and adverse drug reactions
- No studies have investigated pharmacogenetic outcomes for patients with ASD
- Black families are underrepresented in current pharmacogenetic research, which effects clinical utility for this population.
- **Primary Objective for Study 1**: Investigate demographic, genotype/phenotype, and clinical outcomes for patients with ASD in a large precision medicine clinic.
- **Primary Objective for study 2**: Identify modifiable barriers and facilitators to increase access to pharmacogenomic testing, openness to research participation, and the downstream benefits of this evolving science for Black individuals on the spectrum.

Methods

- **Study 1**: Retrospective, observational cohort study utilizing the GOLDILOKs® Clinic database and previously obtained pharmacogenetic testing results
- **Study 2**: Survey of 500 Black/African American-identifying families through the SPARK/SFARI base network (incentivized via a $40 electronic gift card funded by the SPARK DEI Research Match program)
    - Sociodemographic information
    - Medication prescriptions/prescriber information
    - History of mental/behavioral health services
    - General health literacy
    - Pharmacogenomic specific knowledge and perceptions
    - Self-identified barriers or facilitators to obtaining this testing.
- The survey was created with the help of the hospital PFAC

Results

	Black/Afr. Am.	White	Latinx	Multiracial/ Other
Hospital (Overall)	16%	61%	12%	12%
Autism Clinic	14%	66%	12%	8%
Precision Med Clinic	9%	83%	2%	6%



Barrier Survey Question Examples

Is there anything that makes you hesitant to get the testing done? (Check all that apply)

- ○ Unsure why this testing would be helpful
- ○ Unsure why my child needs this testing
- ○ Concern about providing sample (E.g. pain)
- ○ Cost of testing
- ○ Concern about how the information will be used/privacy
- ○ Concern about who will have access to the results
- ○ Obstacles to have testing done– distance, transportation, time off work, etc
- ○ Other – Specify

What would make you more likely to get this test for your child? (Check all that apply)

- ○ More information/education about the testing itself
- ○ More information about the benefits of testing
- ○ More information about what results mean
- ○ Lower cost
- ○ Less invasive collection (E.g. cheek swab vs. blood draw)
- ○ Friends or family who have had the testing completed before
- ○ Other – Specify

		n (% of sample)	Median (IQR) number of psych medication ADRs	Median (IQR) number of non-psych medication ADRs
Sex	Female	63 (31%)	2.0 (1.0, 3.0)	2.0 (1.0, 4.0)
	Male	139 (69%)	2.0 (1.0, 4.0)	2.0 (1.0, 5.0)
Race & ethnicity*	Black	18 (9%)	2.0 (1.3, 3.8)	1.5 (0.3, 5.3)
	Other	13 (6%)	1.0 (1.0, 2.0)	2.0 (1.0, 4.0)
	White	168 (83%)	2.0 (1.0, 3.0)	2.5 (1.0, 5.0)

Discussion & Next Steps

- **Study 1** is ongoing; will continue to conduct analyses to investigate significant differences, and characterize pharmacogenetic testing results and medication use with consideration of patient age, sex, and phenotype
- Upon initial analysis, sex and race are not associated with a change in risk of ADRs with psych meds; but Black youth appear less likely to have non-psych ADRs as compared to White youth, but this may be related to different rates of utilization
- **Study 2** will investigate the associations between family/child characteristics and health care experiences/perspectives to identify and explore the prominent barriers and facilitators for accessing precision medicine and participating in pharmacogenetic research
- Once barriers and facilitators are identified, strategies will be implemented in order to increase access and knowledge of pharmacogenetic testing and precision medicine clinics to underrepresented minority groups
- Interventions may include community outreach and education followed by re-surveying the community regarding knowledge and access; approaches can also be expanded to other settings and marginalized populations
- With hopes of increasing access and knowledge of pharmacogenetic testing, the goal is to increase the clinical utility of precision medicine through improved representation of clinical and research samples

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PGX: Pharmacogenomic

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