

## Toward Learning What Children Understand About Their Own Participation in a Research Study

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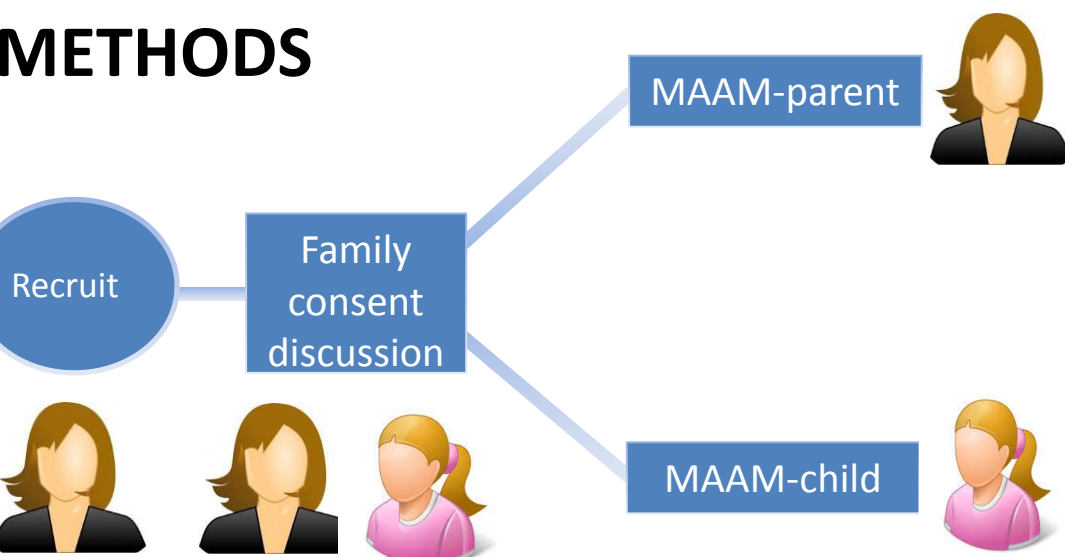
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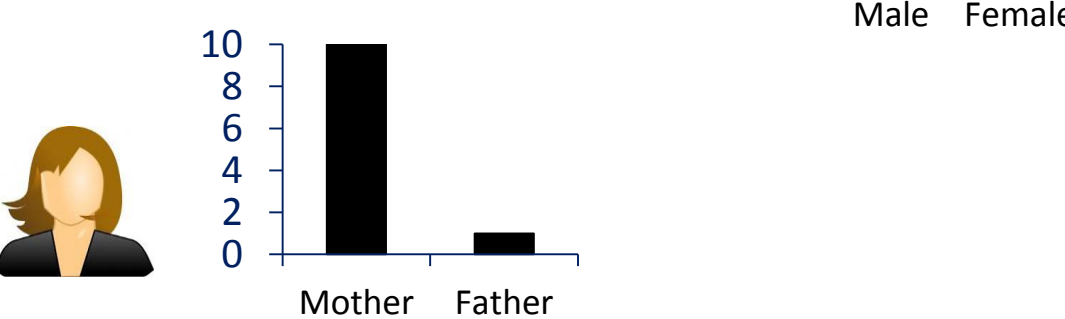
### Rationale

- Research Ethics Boards must ensure researchers make adequate provisions for requesting the assent of capable children<sup>1,2</sup>
- Regulations and policies are vague about what information to disclose and what children should understand<sup>1-3</sup>
- Our research team developed Meaning of Affirmative Agreement Measure (MAAM) as a remedial measure to flag what a child does not understand to prompt researchers to re-explain difficult concepts

### METHODS



Group	n	Mean age
TD	6	10.7 y
CP	5	11.9 y



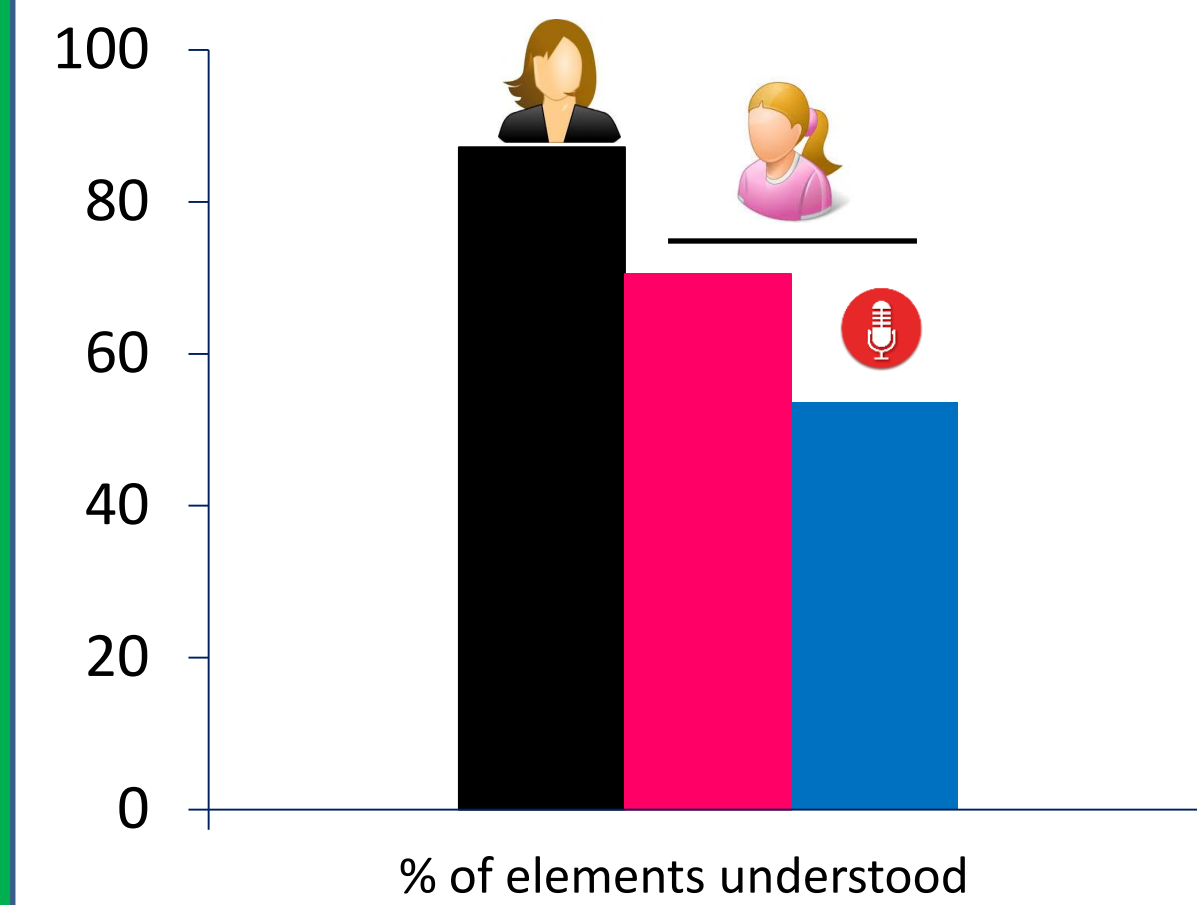
# Parents overestimated their child's understanding about the elements of consent

# Meaning of Affirmative Agreement Measure (MAAM) helps to identify elements that children do not understand



### RESULTS & DISCUSSION

MAAM vs expressed understanding



- MAAM showed that parents overestimated their child's understanding of the elements of consent; no *chance-corrected agreement* between item ratings of parents and children
- Children **explained** 77% of the elements they **reported** as understood using MAAM-c; two children with lower cognitive abilities had more difficulty explaining these elements
- Children/parents said MAAM-c/MAAM-p items were clear
- Revised 7/20 items on MAAM-c based on review of children's **expressed** understanding; revised 3/20 items on MAAM-p to match MAAM-c
- High acceptance of MAAM-c 2.0 /MAAM-p 2.0 items by children and parents

### CONCLUSIONS

- Results support face validity of MAAM-c and MAAM-p
- More studies needed to estimate empirical forms of reliability and validity

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