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Knowledge and perception of the adult lay public regarding assent by minors in biomedical research involving human participants in Lagos, Nigeria

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SESSION 4 Date: 25th Nov 2024

DISCLAIMER/ACKNOWLEDGEMENT

- □ This study was part of the Master's program wholly supported by the Fogarty International Center, National Institutes of Health (NIH), USA [Grant No. 1R25TW010305].
- □ The findings, analysis and conclusion are those of the authors and do not necessarily represent the views of the YU-FIC, NIH or Yenepoya (deemed to be University).
- □ The authors declare no conflict of interest (either financial or non-financial) in this study.

INTRODUCTION

- □ Assent; a child's oral or written agreement to participate in research.
- □ Children's autonomy.
- Relevancy does not necessarily lead to awareness, acceptance, or practice





OBJECTIVE

☐ Assess the knowledge and perceptions of the adult lay public of Lagos, Nigeria, regarding assent by minors in biomedical research involving human participants



METHODOLOGY

Cross-sectional study

Snowball sampling

- □ 339 participants contacted, 131 responded (response rate 38.6%)
- Modified Likert scale validated questionnaire



METHODOLOGY

Informed consent

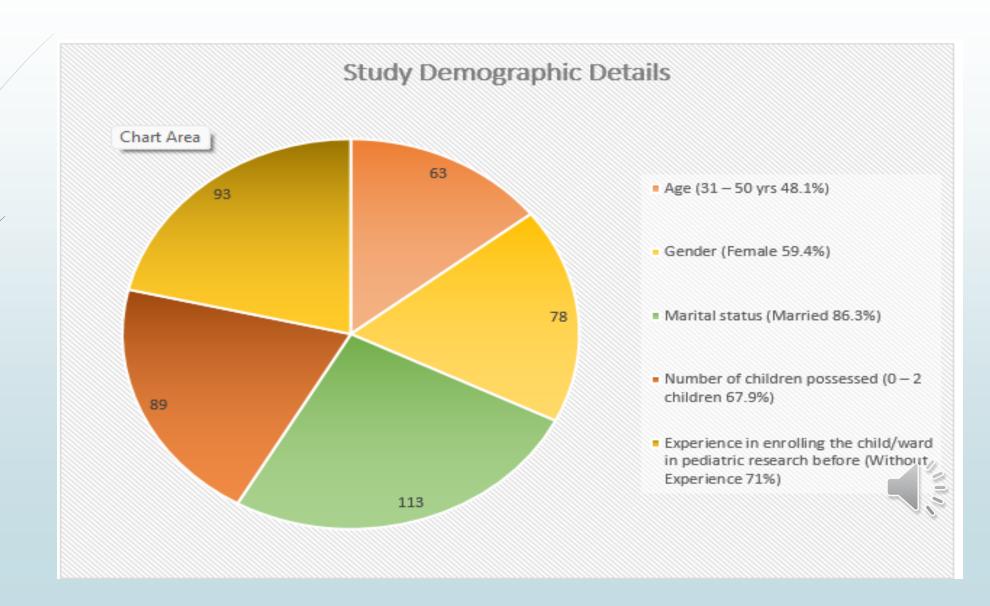
- Bloom's cut-off points for knowledge levels (good: 80-100%, moderate: 60-79%, poor: <60%).
- ☐ Sentiment analysis (perception score)

Decision for the sentiment level

Negatively directed questions = (SA-1, A-2, N-3, D-4 SD-5)

Positively directed questions = (SA-5, A-4, N-3, D-2 SD-1)

RESULTS



RESULTS

- ☐ Average Knowledge score 38.26%
- □ Diverse opinions on who holds the authority to allow a child to participate in research and the importance of obtaining assent from the child.

■ Average Perception score of 3.67.



DISCUSSION

- With an overall knowledge score of 38.26%, significantly below Bloom's cut-off point for good knowledge (80-100%), there seems to be a substantial gap in understanding of the Nigerian adult lay population
- □ In Japan, Fukuda and Fukuda (2018) further highlight this gap, noting that 60% of participants either did not know the term "informed assent" or did not understand the concept
- □ Anderson et al (2012) emphasize the importance of engaging community members in research through certain methods in the USA

DISCUSSION

- □ Their findings show the need for effective targeted education and collaboration to bridge knowledge gaps and ensure ethical research practices in research involving minors.
- Mason and Urquhart (2001) emphasize the importance of a collaborative decision approach in research, which helps to promote and address social justice issues.
- □ Overall average sentiment score of 3.67 suggests a balanced and positive perception towards respecting both parental authority and the child's assent in biomedical research.

DISCUSSION

- □ Unguru (2011) highlights that most decisions in pediatric medicine involve three parties (the clinician, the child, and the parent) in England
- □ The present study shows that, respecting the child's decision to participate was strongly supported, showcasing the importance placed on respecting the child's autonomy and decision-making rights
- □ McCafferty (2024) stressed that the rights of the acknowledge children's voices, contingent upon adults' willingness to respect and consider their views

CONCLUSION

- Substantial lack of clarity around fundamental concepts such as the definition of assent and the roles of parents and minors in the decision-making process.
- □ Significant discrepancy between theoretical knowledge and practical perceptions, as many respondents expressed a preference for collaborative decision-making and respecting children's choices, even with limited understanding of the assent process.

LIMITATIONS OF THE STUDY

□ The study is limited to a particular part of Lagos, Nigeria, which may not be representative of Lagos and other regions in Nigeria or countries with different cultural and regulatory contexts.

□ The cultural norms and values prevalent in Lagos may influence participants' responses and perceptions in ways that may not generalize to other settings.

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