Terminolgy matters in parents' willingness to enroll their children in research

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When presented with different terms to describe a clinical trial, parents were far more likely to consent to enroll their child if it was called a "research study" than if it was called a "medical experiment" or a "research project," in large part because they perceived the former as safer, even though that was not necessarily the case, according to a report in *IRB:* Ethics & Human Research.

Terms such as these are typically used interchangeably in informed consent forms and by researchers describing trials to potential participants and their parents, on the assumption that they mean the same thing. However, parents interpret the terms differently, suggesting that standard descriptions used in informed consent include "information that potentially biases how a parent receives the invitation to participate," the researchers conclude.

For the study, 94 parents who had taken a child to the emergency department at the Children's Hospital of Pittsburgh answered six questions that assessed their willingness to enroll their child in a study and their perception of the following protocol descriptions: research study, research project, research experiment, medical experiment, and medical study.

Only 18 percent of the parents thought these terms were equivalent. Of the parents who did not think the terms meant the same thing, most would allow their child to participate in a "research study" but not in a "research project," a "medical study," or a "medical experiment." The

parents also identified the words "medical" and "experiment" as having negative connotations.

The researchers conclude that "approximately 63% of the respondents rated the protocol descriptors as being different with respect to protocol risk and safety and the inclusion of untested treatments, procedures, and medicines." To minimize bias, the researchers suggest that consent forms use value-free descriptions about research and include a glossary of terms. In addition, they recommend that institutional review boards carefully scrutinize the language in consent forms to ensure that semantic biases are not imbedded in them.

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