Knowledge and Perceptions of Adults from the Middle East Regarding their Rights as Participants in Research

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Submission Type: Scientific
Topic Area: Ethics & Risk
Poster Number: 26

Background: The number of clinical trials has increased in low- and middle-income countries, including those in the Middle East, in recent decades. However, commentators have expressed concerns about the potential for exploitation of populations who face poverty and social deprivation. Safeguards include review of research by functioning research ethics committees (RECs) and informed consent from potential research participants. For a valid informed consent, such individuals need to be knowledgeable about research and about their rights as participants.

Objective: Assess the knowledge and perceptions of potential research participants regarding their rights in research.

Methods: We performed a cross-sectional survey study in university hospitals in Sudan, Egypt, and Saudi Arabia. We developed a survey tool to assess the understanding of adults regarding their rights in clinical research. Systematic random sampling technique was applied in the selected sites. The study was approved by the RECs of the three centers and the REC at a US-based university.

Results: As of this submission, we present the data analysis from 41 participants who enrolled from Saudi Arabia. Regarding attitudes about research: 43.6%, 92.7%, and 85.3% agreed with the importance of drug trials, blood sample research, and survey studies, respectively. Of these participants, 20%, 68%, and 87.8% agreed to be enrolled in drug trials, blood sample research, and survey studies, respectively. Reasons for voluntary participation in research included the opportunity to get better treatment (26%), get extra attention (22%), and help other patients (28%). Regarding informed consent, 20% of participants agreed that those who do withdraw will not receive good care after withdrawal, and 80% agreed that participants should receive a copy of the consent form. When asked about where to file a complaint, 43.9% stated they would contact the investigator; 19.5% would contact the hospital director, whereas, 29.3% stated they would not submit any complaint, as they thought it would have no value.

Conclusions: Potential research participants demonstrated a favorable view of research. Special attention should be given to increase awareness regarding certain aspects of research participants’ rights. Participants need to be counseled on how to operationalize their rights as participants, as few knew who to contact with questions or concerns regarding research complaints.

Limitations: Small sample size and potential issues with generalizability outside the Middle East.

Next steps: Continue active recruitment of potential participants from enrolled sites. Perform qualitative research to address unanswered issues based from the results of this quantitative study.