

# Exploring experiences and perceptions of clinical trial participation: A qualitative study among clinical trial patients

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## ABSTRACT

**Introduction:** Malaysia has recently become one of the active countries running clinical trials (CTs). Efficient and consistent improvement of patient involvement relies on patient expectations and experience in clinical research. This study aims to explore areas of opportunities that could be targeted to improve participation rate in CTs from trial participants' perspective. **Methods:** In-depth semi-structured interviews, covering various sociodemographic backgrounds and therapeutic trials were audio recorded, transcribed and analysed thematically using a phenomenological approach. The participants were recruited until saturation of themes was achieved. **Results:** Five males and five females, aged 29 to 69 years old, participated in the interview. Most participants were aware of the CT process and could associate it with the development of new medicine but the knowledge was limited to the current trial participants. Risk of adverse effects and coordination of care were part of the participants' concern but the majority felt the benefit outweighed the CTs' risk. Individual and relational autonomy has influenced participants' decision-making process related to CTs' participation, while altruism emerge as an important motivation among trial participants. **Conclusion:** The emerging themes provide a foundation for how they perceive participating CTs. The results would be further employed to develop a larger-scale survey study on participants' perceptions of participation in CTs. It is crucial that the public is aware and informed of correct information about CTs. This would lead to increasing participants' retention in CTs and help promote the CTs in the community.