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Highlighting underrepresentation in research for not located population to participate in TB research studies

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Abstract:

Representativeness in research studies is an important concern for researchers, since participation rates have tended to decrease over time. Also, research projects are generally only permitted to analyze data from research participants and not from those who choose to not participate. We aimed to evaluate factors associated with participation versus unlocated populations and characterize the implications for not including the unlocated populations in research studies. We hypothesized that uninvited patients (because they were not located) would have more risk of unsuccessful TB treatment outcomes. After ethics approval, for this study we analyzed anonymized data from TB treatment cards for participants in the PREVENT TB cohort study versus people who did not participate in the same cohort (<http://www.isrctn.com/ISRCTN17820976>) from July 2016 to July 2017. We considered unsuccessful TB treatment outcome as those who died; were transferred; or lost to follow-up during the TB episode, according to the World Health Organization operational definitions. From the total population (n=1026), 73 people didn't participate either because they declined (n=30) or because they could not be invited because they were unlocated (n=43). Among unlocated patients (n=43), 56% (24/43) were male, 37% (16/43) were aged 50 years and 72% (31/43) received first line TB treatment. In regression analysis, those who were unlocated had 34% greater probability of unsuccessful TB treatment outcome in comparison with participants (Prevalence ratio PR:1.34, 95%CI:1.07–1.68, p<0.005). Kaplan–Meier analysis showed that unsuccessful TB treatment outcome appeared in the first months after commencing TB treatment. Furthermore, those who were unlocated had a 61% greater probability of dying compared to those who declined to participate (37%) and compared to the participants of the research study (33%). In conclusion, the enrollment process for participants should be improved for researchers to ensure representativeness of the total population. Unlocated patients should be considered as a priority among healthcare providers to contribute to the END TB Strategy.

Category (Complete): Clinical and Applied Sciences – Pneumonia, Respiratory Infections and Tuberculosis

Presentation Preference (Complete): Oral

Approach (Complete):

Approach: Prevention

Keyword (Complete): not-located ; consent bias ; vulnerable

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