Original Article

Willingness to Participate in Biomedical Research among Adult Population in Bishnupur District, Manipur: A Cross-Sectional Study

Naorem Rishikanta Singh[1], Isaac Lalrawngbawla[2], Vijaya Elangbam[3], Shantibala Konjengbam[4], Hanjabam Sanayaima Devi[5]

[1,2]Post-graduate Trainee, [3]Associate Professor, [4]Professor, [5]Professor and Head, Department of Community Medicine, Regional Institute of Medical Sciences, Imphal, Manipur.

How to cite this article: Naorem Rishikanta Singh, Isaac Lalrawngbawla, Vijaya Elangbam et. al. Willingness to Participate in Biomedical Research among Adult Population in Bishnupur District, Manipur: A Cross-Sectional Study. Indian Journal of Public Health Research and Development / Vol. 15 No. 4, October-December 2024.

Abstract

Context: There are limited data in India, even more so in Manipur when it comes to assessing the willingness to participate in biomedical research despite numerous ongoing research being conducted. This study will throw light on the willingness of the general population who we oftentimes ask to participate in biomedical research.

Aim: To assess the willingness to participate in biomedical research among the adult population of Bishnupur district, Manipur.

Settings and Design: A cross-sectional study was conducted among adults in Bishnupur district, Manipur during March 2023.

Methods and Material: Participants were selected using multistage random sampling with proportional allocation. Data were collected by interviewing the participants using pretested structured questionnaire.

Statistical analysis used: Descriptive statistics like mean with standard deviation and percentage were used. Chi-square test, Fisher Exact test and logistic regression were employed.

Results: There were 448 participants with mean age 42.71±13.74 years. Ninety-two percent previously participated in any form of biomedical research. Participants willing to participate in any biomedical research was 76.1%. Majority of respondents were willing to undergo physical examinations. Risk issuewas the main reason for those not willing to participate. Those who had previous history of participation were ten times more likely to participate than those who had no previous participation in biomedical research.

Conclusions: The study showed that three-fourth of the general adult population in Bishnupur were willing to participate in any biomedical research.

Key-words: willingness, biomedical research, Bishnupur district.

Corresponding Author: Vijaya Elangbam, Associate Professor, Department of Community Medicine, Regional Institute of Medical Sciences, Imphal, Manipur.

E-mail: vijayaelangbam@gmail.com

Submission date: January 9, 2024 **Revision date:** March 19, 2024 **Published date: September 20 , 2024**

Key Messages: Like other studies, willingness to participate in biomedical research was high among adult population. Previous participation in biomedical research was found to be significant with willingness to participate. Exploring all possible barriers and enablers would give researchers better idea on how to design research methodology, thereby enabling better participation.

Introduction

Biomedical research focuses on ways and means to prevent and treat diseases that cause sickness and deaths in human beings and animals. Researchers or scientists use scientific methods to study diseases and biological processes with the aim of developing effective cures and treatment.[1]Biomedical research is an important element in discovering new knowledge or revising current knowledge. Advances in biomedical research highly rely on the successful recruitment and participation of human subjects. Unfortunately, human participation is inadequate and considered one of the main challenges faced by researchers in the biomedical field.[2]

Inadequate involvement or participation in biomedical research can be problematic. For example, insufficient sample size may affect the power of the study, increasing the likelihood of a type II error, and adversely influencing the generalizability of results to the general population. Therefore, it is essential to know and address the factors that affect the willingness of an eligible individual to participate in biomedical research in order to increase the quality of such research.[2]

Review of scholarly articles within the past 10 years shows a rather favourable outcome when it comes to willingness to participate in any biomedical research. However, there are varying outcomes when specifying the type of studies or research designs, severity of disease being studied, and perception of relevance of the topic by the participants. Additionally, sociodemographic factors, including education, income, and religion, may influence participants' decision to provide their consent and to participate in biomedical research[3-15].

There are limited data in India, even more so in Manipur when it comes to assessing or measuring the willingness to participate in biomedical research despite the fact that there are numerous ongoing research being conducted. This study will throw light into the willingness of the general population who we so often ask to participate in biomedical research. This study would have implications on how we can better our research methodology for the future.

This study aimed to assess the willingness to participate in biomedical research among the adult population of Bishnupur district, Manipur and determine the association between characteristics of the participants and willingness to participate in biomedical research.

Subjects and Methods

This is a cross-sectional study done among the general population of Bishnupur district of Manipurfrom 1st to 31st March 2023. Inclusion criteria were adults aged 18 years and above and residing in the district for at least one year. Those who were mentally unfit or decisionally impaired and those who could not be contacted after two visits were excluded. Sample size was calculated at 420, taking the proportion of those who are willing to participate in a personalised health research study of 53.6% (Brall C et al[7]) at 95% confidence interval for two-tailed hypothesis, absolute allowable error 5%, and an estimated 10% non-response rate.

Multistage random sampling with proportional allocation was used to select participants. Bishnupur district has three sub-divisions i.e. Nambol, Bishnupur and Moirang. There were 14 villages in Nambol with 12,589 households, 13 in Bishnupur with 13,009 households and 21 in Moirang with 20,982 households (Census 2011). In the first stage, three villages were selected using simple random sampling from each subdivision. With the help of health workers, a complete list of households in the selected villages was obtained. In the second stage, simple random sampling with proportional allocation was used to select households from the villages, and one eligible member participated from each household. In households with more than one eligible participant, lottery was done to select the participant.

Training was given to Field Investigators before the data collection. After the study purposes

were explained and their anonymity reassured, an informed written consent were obtained from the participants. Field investigators collected data by interviewing the participants using pretested structured questionnaire. Data in the field were collected on google form.

Data from google form were imported into SPSS version 26 for analysis. Mean with standard deviation and percentage were used to describe the background characteristics of the participants. Chi-square and Fisher exact tests were used to find out the significant association between willingness to participate in biomedical research and characteristic variables of the participants at 95% confidence interval. Variables with p-value <0.2 in univariate analysis were put into logistic regression model. P-value less than 0.05 was considered significant.

Ethical approval was obtained from Research Ethics Boards, RIMS, Imphal [No. A/REB/Prop (SP) 197/172/13/2023].

Results

There were 448 participants and mean age was 42.71±13.743 years. Sociodemographic and other characteristics of the participants are given in Table 1.

Table 1: Background characteristics of the study participants (N=448)

Variable	Frequency	Percentage
Gender		
Male	232	51.8
Female	216	48.2
Education		
No formal education	61	13.6
Up to Class 10	97	21.7
Up to Class 12	119	26.6
Graduate & above	171	38.2
Occupation		
Govt employee	57	12.7
Non govt employee	35	7.8
Private / Self-employed	214	47.8
Student	34	7.6
Unemployed/Retired	108	24.1
Marital status		
Never married	100	22.3
Currently married	335	74.8
Widowed	10	2.2
Divorced	2	0.4
Separated	1	0.2
Religion		
Hindu	313	69.9
Sanamahi	99	22.1
Muslim	3	0.7
Christian	33	7.4
Socioeconomic status (BG Prasad scale)		
Class I	138	30.8
Class II	128	28.6
Class III	84	18.8

Class IV	85	19.0
Class V	13	2.9
Perceived health status		
Very unhealthy	12	2.7
Somewhat unhealthy	151	33.7
Neutral	96	21.4
Somewhat healthy	151	33.7
Very healthy	38	8.5
Ever participated in biomedical research		
No	412	92.0
Yes	36	8.0

Willingness to participate in biomedical research was 76.1% (n=341). When further asked about willingness to participate based on nature of participation, most of them were willing to participate when the research involves physical exam (94.4%), personal interview (93.5%), group discussions (88.6%), giving biospecimen (84.5%), coming to an institute (77.1%) and trials (64.2%).

Among those who were willing to participate giving biospecimen, most of them were willing to give urine (99.7%), sputum (97.9%), hair (96.1%), blood (95.8%), stool (92.4%), swabs (93.6%), biopsy (58.7%). And among those willing to participate in clinical trials, when they were asked about the kind of intervention they would be willing to undertake, most of them were willing to go for approved drug (94.5%), new vaccine (65.3%), new drug (50.2%), while a few opted for radiation therapy (6.0%).

Those who were not willing to participate in any biomedical research (23.9%, n=107) were asked the reason why they were not willing, majority of the participants considered it might be risky (72.0%) followed by being afraid to give biospecimen (42.1%), lack of time (38.3%), trust issue (12.2%), indifferent (4.7%), no reason (2.8%), not useful (1.9%) and no incentive (1.9%)

In the univariate analysis, gender and previous history of participation weresignificantly associated with willingness to participate in biomedical research among the participants (Table 2).

Table 2: Association between characteristics of the participants and willingness to participate in biomedical research (N=448)

Variables		**Willingness, n (%)**		**p value**
		No	**Yes**	
Age group	18 - 29 years	13 (14.1)	79 (85.9)	0.079
	30 - 44 years	36 (24.3)	112 (75.7)	
	45 - 59 years	42 (28.6)	105 (71.4)	
	60 years & above	16 (26.2)	45 (73.8)	
Gender	Male	46 (19.8)	186 (80.2)	0.037
	Female	61 (28.2)	155 (71.8)	
Education	No formal education	21 (34.4)	40 (65.6)	0.059
	Up to Class 10	23 (23.7)	74 (76.3)	
	Up to Class 12	32 (26.9)	87 (73.1)	
	Graduate & above	31 (18.1)	140 (81.9)	
Working status	Not working	27 (19.0)	115 (8.0)	0.100
	Working	80 (26.1)	226 (73.9)	

Continue.....

Marital status	Single	26 (23.0)	87 (77.0)	0.801
	With partner	81 (24.2)	254 (75.8)	
Religion	Hindu	69 (22.0)	244 (78.0)	0.265
	Sanamahi	26 (26.3)	73 (73.7)	
	Others	12 (33.3)	24 (66.7)	
Perceived health status	Unhealthy	37 (22.7)	126 (77.3)	0.657
	Healthy	70 (24.6)	215 (75.4)	
Ever participated in biomedical research	No	106 (25.8)	305 (74.2)	0.002*
	Yes	1 (2.7)	36 (97.3)	
*Fisher exact test used				

When the variables were put into logistic regression model, those who had previous history of participation were ten times more likely to participate than those who gave no previous history of participation in biomedical research (Table 3).

Table 3: Logistic regression analysis of participant characteristics and research participation willingness (N=448)

Variables	Crude				Adjusted			
	OR[a]	95% CI[b]		p-value	OR[a]	95% CI[b]		p-value
Age group (years)								
18 - 29	2.161	0.953,	4.897	0.065	1.442	0.584,	3.561	0.427
30 - 44	1.106	0.559,	2.190	0.772	0.920	0.434,	1.949	0.827
45 - 59	0.889	0.453,	1.743	0.732	0.867	0.421,	1.788	0.700
60 & above	1				1			
Gender								
Male	1.591	1.027,	2.466	0.038	1.484	0.921,	2.391	0.105
Female	1				1			
Education								
No formal education	1				1			
Up to Class 10	1.689	0.834,	3.421	0.145	1.543	0.726,	3.283	0.260
Up to Class 12	1.427	0.734,	2.777	0.295	1.149	0.548,	2.408	0.713
Graduate & above	2.371	1.230,	4.569	0.010	1.683	0.784,	3.612	0.182
Working status								
Not working	1.508	0.923,	2.463	0.101	1.410	0.826,	2.406	0.208
Working	1				1			
Ever participated in biomedical research								
No	1				1			
Yes	12.511	1.695,	92.379	0.013	10.565	1.421,	78.571	0.021
a= Odds ratio, b=Confidence interval								

Discussion

Understanding the willingness to participate in biomedical research is important as the advancement in medical science heavily depend on research data. This study represents the attitude of people in rural Manipur towards participating in biomedical research. The findings showed that 76.1% were willing to participate in biomedical research. It was higher as compared to studies conducted by Farha et al.,[2] Cornejo-Torres et al.,[5]and Brall C et al.[6] However, studies conducted by Kongeter et al.,[3] Algabbani et al.,[7] and Teschke et al.[14] showed higher willingness of 96.7%, 92% and 85% respectively.

Among the participants, 8% had previously participated in any biomedical research. The finding is in contrast to studies conducted by Farha et al.,[2] Algabbani et al.,[7] and Gayet-Ageron et al.[10] where 18.1%, 73% and 25% respectively had previously participated in any form of biomedical research.

On nature of participation, 35.8% were willing to participate in clinical trials, out of which 94.52% were willing to go for testing approved drug. But in a study conducted by Gayet-Ageron et al.[10]in Geneva, Switzerland, 44.8% agreed to participate in drug trial while 45.9% in diagnostic study.

Among those participants who were not willing to participate, the main reasons stated were the associated risks with participation (71.96%), being afraid to give biospecimen (12.15%), and not having faith in research activity (12.15%). But in a study conducted by Brall et al.,[6] 46.2% were concerned that their data would not be kept confidential while 45.5% were worried that their data would be misused for commercial and marketing purposes. Fear of medical procedures (48.5%), heard bad things from others (23.8%) were the reasons according to study conducted by Cornejo-Torres et al.[5]

Previous participation in biomedical research was found to be significantly associated with willingness to participate in future biomedical research. The finding is similar to study conducted by Gayet-Ageron et al.[10]However,in other studies (Farha et al.,[2] Chapagain et al.[4]) education, age and gender were found to be significantly associated with willingness to participate in any biomedical research.

This was the first study in Manipur that assessed the proportion of adult population who were willing to participate in biomedical research. Because of this study, it was discovered that many participants who earlier were not aware of biomedical research were made aware. A possible limitation could be that those who participated were, by default of their consent, willing to participate, so the results may be more representative of those who were willing to participate than not. The participants' knowledge of biomedical research could be another limiting factor as their attitude towards participation may change either way had they been more knowledgeable regarding the subject.

Conclusion

Three-fourth of general adult population in Bishnupur were willing to participate in any biomedical research. Previous participation in biomedical research was significantly associated with willingness to participate. Among those who were willing to participate in biomedical research, there were varying proportions of willingness to participate based on the nature of participation (one-on-one interviews, group discussions, medical examinations, giving biospecimens, having to go out of their homes to a hospital/institute and clinical trials).

It is our recommendation that a large-scale study to assess the willingness to participate in biomedical research which would include participants from all districts of Manipur to get a more representative result is needed. As modern medicine is now highly dependent of evidence-based data, more research would be imperative. The assessment of willingness to participate in biomedical research exploring all possible barriers and enablers would give researchers better ideas on how to design research methodology, thereby enabling better participation which would contribute towards more accurate results.

References

1. Scott A. Why We Need Biomedical Research. wordpress.org. WordPress [2021 Jan 2] - . Improving the biomedical research. 2021 Jan 6; [about 2 screens]. Available from: http://www.nhinbre.org/improving-the-biomedical-research/

2. Farha RA, Alzoubi KH, Khabour OF, Mukattash TL. Factors influencing public knowledge and willingness to participate in biomedical research in Jordan: A national survey. Patient preference and adherence. 2020 Aug 5:1373-9.

3. Köngeter A, Schickhardt C, Jungkunz M, Bergbold S, Mehlis K, Winkler EC. Patients' Willingness to Provide Their Clinical Data for Research Purposes and Acceptance of Different Consent Models: Findings From a Representative Survey of Patients With Cancer. J Med Internet Res. 2022 Aug 25;24(8):e37665.

4. Chapagain RH, Adhikari S, Giri BR, Ray P, Shrestha NJ, Prajapati B et al. Factors affecting willingness to participate in vaccine clinical trials in an underdeveloped country: perspective from Nepal. Hum Vaccin Immunother. 2022 Nov 30;18(5):2051413.

5. Cornejo-Torres Y, Boniface E, Lopez E, Gomez-Arboleda K, Darney BG. Willingness to Participate in Health Research: Mexican and Mexican American Women's Perspectives. Women's health rep. 2022 Sep 1;3(1):785-94.

6. Brall C, Berlin C, Zwahlen M, Ormond KE, Egger M, Vayena E. Public willingness to participate in personalized health research and biobanking: A large-scale Swiss survey. PLoS One. 2021 Apr 1;16(4):e0249141.

7. Algabbani A, Alqahtani A, BinDhim N. Willingness and determinants of participation in public health research: a cross-sectional study in Saudi Arabia. East Mediterr Health J. 2021 Jan 23;27(1):59-66.

8. Bailey JC, Crawford DC, Goldenberg A, Slaven A, Pencak J, Schachere M et al. Willingness to Participate in a National Precision Medicine Cohort: Attitudes of Chronic Kidney Disease Patients at a Cleveland Public Hospital. J Pers Med. 2018 Jun 26;8(3):21.

9. Scanlon JK, Wofford L, Fair A, Philippi D. Predictors of Participation in Clinical Research. Nurs Res. 2021 Jul-Aug 01;70(4):289-297.

10. Gayet-Ageron A, Rudaz S, Perneger T. Study design factors influencing patients' willingness to participate in clinical research: a randomised vignette-based study. BMC Medical Res. Methodol. 2020 Dec;20:1-8.

11. Milani SA, Swain M, Otufowora A, Cottler LB, Striley CW. Willingness to participate in health research among community-dwelling middle-aged and older adults: does race/ethnicity matter?. J Racial Ethn Health Disparities. Jun;8:773-82.

12. Bouida W, Grissa MH, Zorgati A, Beltaief K, Boubaker H, Sriha A et al. Willingness to participate in health research: Tunisian survey. BMC medical ethics. 2016 Dec;17:1-5.

13. Sellars B, Garza MA, Fryer CS, Thomas SB. Utilization of health care services and willingness to participate in future medical research: The role of race and social support. J Natl Med Assoc. 2010 Sep 1;102(9):776-86.

14. Teschke K, Marino S, Chu R, Tsui JK, Harris MA, Marion SA. Public opinions about participating in health research. Can. J. Public Health. 2010 Mar;101:159-64.

15. Katz RV, Green BL, Kressin NR, Claudio C, Wang MQ, Russell SL. Willingness of minorities to participate in biomedical studies: confirmatory findings from a follow-up study using the Tuskegee Legacy Project Questionnaire. J Natl Med Assoc. 2007 Sep;99(9):1052-60.