**Name of the study:** Survey of Public Knowledge and Perception of Clinical Research in Mumbai

**Note:**

**Please answer the below mentioned questions in 15- 20 Minutes.**

**Please tick or write the appropriate option for each question as applicable.**

1. Have you heard about clinical research? **Yes / No**
2. [If ‘Yes’]: What was the source:

* Doctor
* media
* internet
* relatives
* friends
* colleagues
* other:

[A standard definition of clinical research will be read to the person and opportunity is provided to ask questions and/or contact a clinical research professional for further clarifications]

**Definition:** Clinical research is a scientific method of studying the effects, both positive and negative, of proposed new treatments [medications or devices] in human volunteers (healthy individuals or patients). Government authorities require convincing demonstration of benefit of a new treatment before giving approval to use it in the public at large. If adverse effects are found with a new treatment then the benefits should outweigh the risk of adverse effects. Clinical trial, clinical study, and clinical research are all similar terms. Every medication in every pharmacy had to go through the clinical research process. Do you have any questions?

1. Have you ever participated in clinical research? **Yes / No**
2. Do you know what clinical research is? **Yes / No**
3. Do you know anyone who participated in clinical research? **Yes / No**
4. [If yes]: How many?
5. Do you know individuals who believe they were coerced to participate in clinical research? **Yes / No**
6. [If ‘Yes’]:Who were they coerced by:

* Doctor
* recruitment team
* relatives
* friends
* not aware

1. Will you be willing to participate in clinical research? (Answer ‘Yes’ if there is any reasonable circumstance under which you see yourself participating) **Yes / No**
2. [If Yes]: What kind of involvement in clinical research would you be willing to undertake? (Choose all appropriate answers; choose an answer if there is any reasonable circumstance where you see yourself accepting the option)

* Single questionnaire (up to 20 minutes in duration)
* Single blood draw
* Single visit (up to a few hours in duration with multiple interventions)
* Multiple visits (each up to a few hours in duration)
* Multiple days of stay in a confined unit (including overnight stay)
* Research done together with administration of standard medical care
* Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. If No, will you state any particular reason/s?
2. Would you have to take permission from someone else in order to participate in research? **Yes / No**
3. If yes who would it be

* spouse,
* parents,
* children,
* friends,
* physician,
* others

1. Minimal compensation appropriate for one-day’s participation in a clinical trial (no overnight stay) is:

* Altruism
* The worth of one day’s work plus expenses
* Less than the worth of one day’s work plus expenses
* More than the worth of one day’s work plus expenses
* Just expenses (e.g., travel, parking expenses)
* Free medical care
* Depending on expected benefit (less benefit = more compensation)
* Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Please indicate if you believe the following statements are true, false, ‘not aware’, or ‘not relevant’:**

1. If you decide not to participate in research your doctor will not give you good care

1. Confidentiality is a matter of importance to research participants
2. Confidentiality of research participants is adequately protected
3. Clinical research information provided by pharmaceutical companies can be trusted
4. Clinical research information provided by academic institutions can be trusted
5. The most important reason for developing new treatments is financial gain
6. Clinical research benefits society
7. Volunteers in clinical research get adequate compensation for their participation
8. Clinical research is an essential step in developing new treatments
9. Human participants in clinical research are treated like experimental animals (‘human Guinea Pigs’)
10. The most important reason for developing new treatments is the advancement of science
11. Altruism is the only valid reason for participation in research
12. Volunteers in clinical research get adequate information about the research they participate in
13. Participation in research is entirely voluntary
14. Participants in clinical research get adequate compensation for any adverse outcomes
15. Clinical research harms society
16. The government always adequately protects the public against unethical clinical research
17. Hospitals that participate in clinical research provide better healthcare
18. All the results of clinical research are made available to the public
19. Doctors force their patients to participate in research
20. You have had an opportunity to participate in clinical research
21. Researchers make sure research is safe for participants
22. The media accurately describes clinical research
23. Experiments on humans are essential to developing new treatments
24. Harmful events occurring during a clinical trial must be due to experimental treatment
25. The public should be involved in clinical research (eg: design, oversight and funding)
26. Other beliefs or statement you wish to make regarding clinical research:

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1. What is the impact on clinical research for collaborations with non-Indian Industry partners?

* Good
* Bad
* None
* Not aware

1. Statethe extent of the impact**:**

* Large
* Moderate
* Minimal

1. What is the impact on clinical research for collaborations with non-Indian academic partners?

* Good
* Bad
* None
* Not aware

1. State the extent of the impact:

* large,
* moderate
* minimal

1. **What does ‘human guinea – pig’ mean to you (include all)?**
2. Being used without your consent or understanding
3. Being used for someone else’s benefit
4. Possibility of being exposed to unsafe interventions
5. Being disrespected
6. Being subjected to uncomfortable situation/condition
7. Other
8. **The public should be involved in the following clinical research activities (include all that apply)**
9. As participants/Volunteers in clinical trials
10. Advocating for research public policy
11. Providing funds for clinical research
12. Collecting data
13. Are there any other comments you would like to bring to our attention:

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**I hereby state that the above mentioned answers have been duly filled in by me and reflect my personal opinion.**

**Name and signature of the participant:**

Date:

Place: