

THREE PRINCIPLES OF RESEARCH ETHICS

- Respect for Persons and Their Community
- Beneficence
- Justice

Principle 1: Respect for Persons and Their Community

- Respect for rights of the beneficiaries of the Board of Guardians programme recognizes the right to:
 - Autonomy, self-determination
 - Capacity to decide and make choices
 - Dignity and Respect
 - Respect for the Community and the Local Culture of the Respondents Regardless of national/linguistic origin

Principle 2: Beneficence

- This principle holds the researcher **responsible for the physical, mental, and social well-being** of the respondents throughout participation in the survey.
- **Benefits and risks** to the respondents must be carefully assessed.
- The expression “**DO NO HARM**” applies to this principle of Beneficence.
- **The protection of the well being of the respondent is paramount.** Protecting the respondent is more important than collecting the data pursuing the research and whatever benefits that might derive to the Government or the U.N.

The Ministry of Social Transformation, UN Women and Each enumerator must ensure the following:

• CONFIDENTIALITY and PRIVACY:

- Your role is to collect the data; and in a manner that is respectful and confidential.
- Discussing the experiences of the respondent with others in a manner that reveals their names and their individual situation is not allowed.
- Enumerators will be asked to sign confidentiality agreements prior to the conduct of the survey, with violations resulting in a severe penalty.

• INFORMED CONSENT:

- You must get the consent the respondent.
- You cannot force or coerce the respondent to do the survey. If they refuse to participate, stop the survey.

• PHYSICAL and MENTAL WELL-BEING OF THE RESPONDENT:

- Stop the survey if you notice that continuing it would place the respondent in danger.

Principle 3: Justice

- According to this principle, one group of research participants cannot be placed at risk solely for the benefit of others. For example, in the early 20th century, poor hospital ward patients often served as research subjects (e.g. 1932-1972 Tuskegee Study), with the benefits of the research benefiting the private patients.
- Poor communities cannot be used for research purposed that redound to the benefit of more privileged communities.
- The risks and benefits of the research must be distributed equitably and for the benefit of both potential participants and communities.



Vulnerable Research Participants

The Council for International Organizations of Medical Sciences (CIOMS) defines **vulnerability** as “**substantial incapacity to protect one’s own interests owing to such impediments as lack of capability to give informed consent, lack of alternative means of obtaining medical care or other expensive necessities, or being a junior or subordinate member of a hierarchical group.**”

EXAMPLES OF VULNERABLE RESEARCH PARTICIPANTS

- -The Poor
- -Survivors of Gender Based Violence
- -Pregnant Women
- -Persons with disabilities
- -Children
- -Prisoners
- -Mentally Ill
- -Populations with limited education
- -Those with limited access to health services
- -Sex workers
- -Undocumented migrants



Sample Consent Form

CONSENT FORM

•Beneficiary ID: _____

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•The Ministry of Social Transformation and Human Resources is conducting a survey about living standards and health in Antigua and Barbuda. The information we collect will help the government to better plan services. Your household was selected for the survey. I would like to ask you some questions about your household. The questions usually take about 25 to 30 minutes. All of the answers you give will be confidential and will not be shared with anyone other than members of our survey team. You don't have to participate in the survey, but we hope you will agree to answer the questions as your views are important. If I ask you any question you don't want to answer, just let me know and I will go on to the next question or you can stop the interview at any time.

Do you consent to participate in this survey? (If the answer is no, that means the interview had ended).

Yes

No

This questionnaire will request some information on the education and health status of children under 18 years living in this household. Do you consent to provide such information?

YES

NO

Signature:



Considerations For Data Sharing

Incoming Data

- Ensure the data received is legitimate
- You should ideally be asked to sign a Data Sharing Agreement asking you to ensure privacy of the data being received.
- Make sure the data/information is stored securely.
- Inform the data provider when the data is discarded after use.



Outbound Data

- Put in place a data sharing agreement or protocol ensure that the data you are sharing with the third party will be treated securely and not shared without consent with any other party.
- Ensure data being provided publicly is anonymised.



Example of Confidentiality Oath

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THANK YOU