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Developing and Testing Informed-Consent Methods in a Study of the Elderly in Mexico: Appendixes

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Sponsored by the Government of the State of Yucatan and the National Institute on Aging
List of Appendixes

• Appendix A: Original Informed-Consent Documents (English Version)

• Appendix B: Revised Informed-Consent Documents (English Version)
INFORMED CONSENT

(PRETEST VERSION)

Program for the elderly poor

You are being asked to participate in a research study conducted by ______, from the Division of Labor and Population at RAND, Santa Monica. We are asking your permission to be in a research study about _____. You were selected to be part of this study because you are currently enrolled in the Program for the Elderly Poor in the State of Yucatan. Your receipt of services from this Program will not be affected in any way by your decision to participate in this study. Please read (or listen to) the information below, and feel free to ask any questions if you do not understand something before deciding whether or not you want to participate.

PURPOSE OF THE STUDY

The purpose of the study is to learn about the effects on health, expenditures, and sources of income during retirement of the poverty alleviation program for the elderly in Yucatan.

PROCEDURES

If you volunteer to participate in this study, we will ask you to answer a survey that contains questions on topics related to socio-economic characteristics or your household, sources of income, demographic characteristics of household members, your own health, and your performance of daily activities. This information will be useful to describe the population that is being served by the program. The survey will last about 70 minutes. If you need assistance to answer any of the questions, you may ask one of your household members to assist you.

POTENTIAL RISKS AND DISCOMFORTS

It is possible that some of the topics of the survey may address issues that could be upsetting to you. For example, talking about household members who do not live with you, or about some aspects of your own health might be upsetting. You are free to skip or refuse to answer any question that you wish. You may also choose to stop taking part in this study at any time, without any negative impact on your benefits from the program.
ANTICIPATED BENEFITS TO SUBJECTS

There are no direct benefits from your participation in the study.

ANTICIPATED BENEFITS TO SOCIETY

Information from this study may provide the basis for building a larger study to understand the transition to adulthood for Hispanic youth.

ALTERNATIVES TO PARTICIPATION

You can decide not to take part in the survey.

PAYMENT FOR PARTICIPATION

There is no money offered for participating in this study.

PRIVACY AND CONFIDENTIALITY

We will keep all written information about you (including your contact information) completely confidential. We will separate your contact information from your survey responses. All information will be stored in a locked file cabinet in Dr. Aguila’s office at RAND. Surveys will be shredded within one year of completion of data collection.

We will be writing reports about this study. The information presented in these reports will only discuss information about the entire group of participants. No information on a single person will be made available. Therefore, no information of a confidential nature about you will be disclosed. When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

PARTICIPATION AND WITHDRAWAL

Your participation in this research is VOLUNTARY. We anticipate to conduct house visits every year, for the following five years. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without prejudice to your benefits obtained through the program.
Please check one of the following:

_____ I do give permission to be contacted in follow-up visits by members of the research team for the following five years.

_____ I do not give permission to be contacted in follow-up visits by members of the research team for the following five years.

IDENTIFICATION OF INVESTIGATORS

If you have any question or concerns about the research study, please feel free to contact:

Dr. Emma Aguila, Primary Investigator
1776 Main Street, M3W
Santa Monica, CA, 90407-2138
eaguila@rand.org
(310) 393-0411 extension 6682 during regular business hours.

If you have any other questions about being in the research study, you may contact Jim Tebow, Co-Administrator, RAND Human Subjects Protection Committee, 1776 Main Street, M3W, Santa Monica, CA, 90407-2138, (310) 393-0411 x 7173, Jim_Tebow@rand.org

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal rights because of your participation in this research study. If you have questions regarding your rights as a research subject, contact: Jim Tebow, Co-Administrator, RAND Human Subjects Protection Committee, 1776 Main Street, M3W, Santa Monica, CA, 90407-2138, (310) 393-0411 x 7173, Jim_Tebow@rand.org
If you wish to participate in the survey, please sign below:

________________________________________________
First and last name     Signature
__________________________________
Witness Date

Person who signed: □ Respondent  □ Proxy
Respondent

Thank you for your help!
Dear Participant:

Thank you again for participating in the Survey of Socioeconomic Characteristics of the Household in the State of Yucatan (ENCAHEY). We’d like to remind you that the information obtained through this survey will be treated as confidential. For the purpose of improving the conditions of the people of the State of Yucatán, we will be using the information gathered as part of this survey to conduct research on issues related to the health, housing, education, social security, and other topics.

For this reason, it would be extremely useful to be able to access your administrative records from health, social security, education, and other government programs. This information will also be confidential and will only be used for research purposes. No one outside the research study will have access to this information.

If you agree to give us permission to access your administrative records from government programs related to health, social security, financial support, please sign below:

[Signature]
Print first and last name

Mr./Mrs.: ___________________________ is not able to read nor write and therefore provides his/her fingerprint insted: __________

Signing in his place: ___________________________ son/daughter/other relative of Mr./Mrs. ___________________________.

Thank you for your collaboration!

Research Committee for the Survey of Socioeconomic Characteristics of the Household in the State of Yucatan (ENCAHEY) and the Government of the State of Yucatan.