



Health Screening and Baseline, 3 month, and 6 month Data Entry Protocol

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INTRODUCTION/ OVERVIEW

The data collection from every health screening activities conducted by Project AsPIRE has three phases. The first phase consists of trained staff or volunteers explaining the consent form, confidentiality agreement, and liability release to the participants, and obtaining the participant's signature. Then, the interviewer administers the screening tool with the participants. Once the screening tool is complete, participants are led to the second phase to get their height and weight, blood pressure, serum glucose and cholesterol measurements. The last phase consists of an exit interview where trained staff provides health education related to the participants' risk factors, an explanation of the participant's readings, and an explanation of the purpose of the study. Participants are then asked if they are interested in participating in the research study if they qualify. If interested, the volunteer will administer the baseline survey immediately. Lastly, participants receive some incentives and a referral to a doctor if needed.

(See Chart 1)

Data are collected in six areas: (a) demographics, (b) acculturation factors, (c) knowledge/awareness of hypertension, (d) access to health care, (e) lifestyle, and (f) clinical. Each of these areas is described below:

- (a)** Demographic questions included the participant's home address, telephone number, gender, race/ethnicity, birth place by region, age, employment and marital status.
- (b)** Acculturation factors included questions on language, the year of entry and number of years lived in the US in the case of immigrant participants.
- (c)** A "yes" or "no" questionnaire captures one's knowledge/awareness of hypertension. In addition, self awareness questions on high cholesterol, diabetes, stroke, congestive heart failure, and heart attack are included in this category. This section also includes the personal and family medical history, along with a question on family mortality.
- (d)** To measure the participants' access to healthcare, they were asked if they currently have health insurance and where they seek healthcare.
- (e)** Two questions about lifestyle assessed cigarette use, alcohol intake, and frequency of physical exercise.
- (f)** The clinical measures include blood pressure, serum glucose, total cholesterol readings, and BMI.



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Data Collection Procedures

Training on survey administration:

1. Volunteers and staff should be familiar with the screening tools. A one-hour training given by the Outreach Coordinator is required for all those willing to be interviewers during health screening events.
2. Volunteers and staff should all be HIPAA certified without exemption.
3. They should have undergone an hour of training on how to administer the screening tool
4. Health providers (nurses, doctors) should also be familiar with the screening tool and it is the duty of the Project Director (PD) or the Outreach coordinator (OC) to train them before the health screenings

Survey administration:

5. Interviewers must ensure that their handwriting is legible.
6. Before administering the screening tools, interviewers MUST explain the consent form, the confidentiality agreement, and liability release all contained in the first page, and MUST obtain the participant's signature and the date.
7. Interviewers should not leave any field blank. It is their responsibility to review for completeness the screening tool before the participant can even go to see the health providers. If they inadvertently miss a field, they must approach participant while they are still onsite to complete the section.
8. In case of refusal to answer specific fields, Please write down 98.
9. It is the responsibility of each interviewer to make sure that participants will not leave the site with the screening tools on hand.
10. After completing the instrument, the interviewer MUST write his/her complete name, NOT the signature, in the lower section of the first page that says "Witnessed by".
11. Screening tools must not be self-administered. Interviewers will be the ones administering the screening tools, asking the participants all the questions.
12. The last section of the screening tool requires that participants provide the best way to contact them. Interviewers must clearly ask each participant about their preference on how to be contacted either: 1) through home phone number, 2) cell phone and the best time to call them, 3) through text messaging, 4) email, 5) or mail.



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Referral Process

13. During and after the health screening, the CHW will refer to the screening tools to assess and gather information from the participants needing immediate attention.
14. It is the duty of the CHW to remind the health providers to fill up 2 copies of the referral form with a short waiver, one to be given to the participants who need it, and the other will be kept for file.

Transporting data

15. Once the health screening is over, it is the duty of the PD or the OC to bring all the screening tools back to the office to be entered on the next business day that follows the health screening.

I. Level of Clearance and Access

- A. The data set will be secured and protected in the main server provided for by the NYU Langone Medical Center.
- B. As a precaution to protect the privacy of the study participants, the data set containing the screening data should not be emailed or shared through printouts in part or in whole to other staff members requesting the participants' data information.
 1. Only the following staff: the Program Director (PD), the Research Analyst (RA), and the Database manager (DM) will have a security clearance to access and to create change in all the data including the screening data contained in the main server. Data transcribers like interns and volunteers (all HIPAA certified) will have access to database solely for the purpose of entering the data in the presence of the Data Manager or the research analyst.
 2. CHWs will have direct and remote access to the main server to enter information about the study participants' logs, checklist, and reports about their one on one visit with the participants. CHW will also have access to browse at the database for their reference but not to change any pertinent information. ALL changes should be



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done by or with the approval of the Research Analyst or the Database manager.

II. Data Entry, Storage, and Access

All data collected from the screening tools have to be entered into the officially approved data set created by the Project team. There should be ONLY one version of the data set in the ACCESS program. No other screening data collected throughout the year should be entered in other programs like Excel. Except when doing the final analysis, cleaned data should be transferred to SPSS.

All screening data collected should be entered in the data set on the next business day that follows the health screening.

- A. All transcribers such as interns, volunteers, and staff must possess HIPAA certification prior to accessing any of the screening data.
- B. All transcribers should be familiarized with the Screening Data Codebook. They will be trained by the Database manager.
- C. All data should be transcribed as faithfully as possible from the original source document to the data set, with as little interpretation as possible. The data transcriber should enter only what is in the original source document.
- D. If the transcriber of the database wishes to add conjectures, interpretation, or editorial comments, these all should be made within square brackets ("["]"), to indicate that these comments are **not** part of the original source.

Missing Data

If a data item is missing in the original source, indicate this with the number 99, rather than leaving a blank field or using any other indicator.

Illegible Data

If a data item is illegible or questionable in the original record, transcribe as much as you can, and use the following indicators:



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- a. Questionable entries should be followed by a question mark ("?").
- b. If a data item is totally illegible, just place a single question mark in the cell.
- c. Use an ellipsis ("...") to indicate illegible parts of a name.
For example, write "SM...TH", if you can't determine what the letters are between the "SM" and "TH".
- d. If you can't decide which of two possibilities a partially legible name represents, write **both** interpretations, separated by a slash and spaces.
For example, write "STEIN? / STERN?" or "PERL? / BERL?".

III. Data Clarification

1. In the event that there are missing/illegible data, it is the duty of the transcriber to inform the Database Manager or the Research Analyst about the missing/illegible data. It is then the responsibility of the Database Manager or the Research Analyst to call the participants NOT later than one week after the screening date to clarify or to correct the errors.
2. The correction should be annotated with time and date on both the original document as well as in the data set. The date and time the DM or RA called the participants should also be annotated ONLY in the original document.

Data Clean Up

Data auditing is an important process to ensure that collected data represents the actual responses given by participants. Auditing includes searching of logical inconsistencies in the data and reconciling responses from documents and data entry.

After new data has been entered, short-hand auditing will occur within a week of entry. Short-hand auditing entails choosing random participant responses and reconciling them with the responses from paper documents.

Comprehensive auditing will occur every three months. Comprehensive review includes looking at every participant response and checking it against paper



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documents. In addition, the review will look at logical inconsistencies in the data. Data entry interns and assistants are responsible for conducting the auditing procedures. The research analyst is responsible for reviewing data.

Data Analyses

Data analyses should be conducted under two protocols. The first protocol is on-demand. On-demand analyses include analyses for meetings and presentations. Regular protocol refers to the schedule time for report production.

Data analyses are usually handled by the research analyst or data manager. However, research associates may also conduct analyses, if trained.



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Baseline/ 3month/6month Surveys

INTRODUCTION/OVERVIEW

The baseline, 3 months, and 6 months surveys will be used to conducting formative research necessary to inform the development of a community health worker intervention to improve health access and status for cardiovascular disease in the Filipino American community living in New York City and New Jersey.

Procedures in administering the Baseline survey

I. Preliminary

1. The baseline survey is given to those participants who are found eligible¹ and are willing to participate in the research study. During the health screenings, a participant who is found to have untreated or uncontrolled hypertension will be asked if he/she is willing to be part of the research study. If he/she agrees, the volunteer will administer the baseline survey.
2. Survey tools must not be self-administered. Interviewers will be the ones administering the screening tools, asking the participants all the questions.
3. Health screening interviewers must be trained by the Database Manager to be able to explain with clarity the purpose of the study and what it takes to accomplish it. Interviewers should be able to explain any risk involved and the commitment that the study will require from each participant (See *Appendix__*). Interviewers should also be ready to answer truthfully any question each potential participant will pose. If an interviewer is not sure of what to answer, ALWAYS refer the matter to the project director or to the community health workers.
4. There will be a pool of volunteer interviewers and they will be assigned to attend various health screening events to administer the baseline survey.
5. ALL survey interviewers must be bilingual or have at least a basic knowledge and understanding of Filipino.

¹ Criteria for eligibility are: of Filipino descent, 25-75 years of age, resident of Jersey City, NJ or Queens, NY, not on renal dialysis, have not experienced stroke, congestive heart failure, heart attack, or any cardiac operation, and have not participated in any cardiovascular disease or hypertension study before. Based on the Guidelines published by the JNC7, the diagnostic threshold for hypertension was ≥ 140 mmHg (systolic blood pressure) or ≥ 90 mmHg (diastolic blood pressure).



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6. If the qualified participant agrees to be in the research study, the interviewer will explain the content of the consent form and requires the participant's signature.
7. ONLY after the participant signs the consent form, the baseline survey will be administered.

II. On administering the Baseline Survey

The Baseline survey is consisted of the following topics: Clinical measures, demographic and social variables, risk factors, weight management, health access and utilization, appointment keeping, cardiac medication self efficacy, stress, mental health questions, self efficacy and health decision making, health status, past health screening behaviors, and psychosocial variables. Each field from these specific topics should be answered properly and completely.

1. The interviewer should introduce him/herself to the participant. An example could be:

"My name is _____. I am with the NYU Center for the Study of Asian American Health. Or I'm with Kalusugan Coalition and I'm a volunteer for Project AsPIRE.

Thank you again for agreeing to participate in this study. The survey will take approximately 30 to 45 minutes to complete. For your time, we will be providing you with an international phone card. Again, the information you provide in the survey is completely confidential."

2. The interviewer will remind the participant that if any time during the course of the interview, he/she is confused about a question, he/she should tell the interviewer.
3. The interviewer should also remind the participants that if there are questions he/she does not feel comfortable answering, he/she has the option to skip the questionnaire, and all his/her answers will be kept confidential.
4. Complete all the fields carefully either by checking or writing (as the case maybe) without leaving any field blank.
5. During the volunteer trainings, potential interviewers will learn how to fill complete the survey and they will be familiarized with the skip patterns



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- (skip=97) in the baseline survey so that no field will be left blank without the proper annotation.
6. Interviewers should start with page 4 the “Demographic and Social variables (Part 1 of 2)” and leave the Clinical Measure to the end. After finishing the interview, interviewers should accompany the participant to the health provider to get and record their clinical measures in their baseline.
 7. In the event that the participant has already completed his/her 3rd screening tool that same day, the interviewer will then transfer the existing clinical measures by copying them to the baseline form. Except for waist and hip measurements that are not included in the screening tools, the interviewer can take those measurements and record them properly.
 8. Do not forget to thank the participant after the interview. The interviewer may now invite the participant to attend an orientation workshop and introduce them formally to the community health workers.
 9. In the event that the participant refuses to continue with the survey, please make annotations on page 2 of the comments’ section. Ask the participants the reason for not continuing, e.g. too long and running out of time to do grocery, etc. Ask also the participant when and where would be the best time to contact and to see her to finish the interview. SUBMIT immediately the unfinished survey to the CHW after writing down the comments and inform them about the case.
 10. If at the onset of the interview, the qualified participant refused to do the survey, ask for their reasons POLITELY; then record it on the refusal section of page 2. Thank the participant, assure them of our continuous support and tell them that if at any time, they wish to do the survey, they can inform the CHW and from time to time, our CHW will ask about their disposition on completing the survey.

Qualified participants who refuse to do the baseline survey but are interested in attending the sessions can be part of the pool of volunteer participants.

III. On checking the specific fields of the Baseline Survey

There are some important sections of the Baseline survey questionnaires whose answers may require an immediate attention on the part of the community health workers.



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1. After every health screening where baseline surveys are collected, it is the duty of the Program Director or the Outreach Coordinator to bring all the baseline surveys back to the office to be reviewed on the next business day that follows.
2. Reviewers (Project Director, CHW, Research Analyst, Outreach Coordinator) will look at every survey forms to check for any missing information. It is the reviewers' duty to call back the participants within a week to complete the missing information.
3. Specific sections may need immediate attention. During the course of the survey form review, reviewers will need to specifically look at the following items:
 - a. Blood pressure readings, blood sugar and cholesterol readings
 - b. Mental Health questionnaires

Reviewers should immediately communicate by phone the adverse results within a day to the CHW for an immediate same day follow up.

4. After steps 1, 2, & 3 are taken, it is the duty of the Database Manager to produce an intervention check list containing the names and personal data of every participant who filled up the baseline survey. This data set will be available on the main server of Project AsPIRE that can be access remotely by the CHW for their reference.
5. Within that week, the data collected through the baseline survey will be entered by staff or volunteers. Data entry should be finished before the orientation workshop starts for that specific cohort.

IV. Level of Clearance and Access

- A. The survey data set will be secured and protected in the main server provided for by NYU School of Medicine.
- B. As a precaution to protect the privacy of the study participants, the data set containing the survey data should not be emailed or shared through printouts in part or in whole to other staff members requesting the participants' data information.
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clearance to access and to create change in all the data including the survey data contained in the main server. Data transcribers like interns and volunteers (all HIPAA certified) will have access to database solely for the purpose of entering the data in the presence of the Data Manager or the research analyst.

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All survey data collected should be entered in the data set before the orientation workshop for that specific cohort starts.

- A. All transcriber such as interns, volunteers, and staff should possess HIPAA certification before they are even allowed to look at the survey data.
- B. All transcriber should be familiarized with the Baseline Survey Codebook.
- C. All data should be transcribed as faithfully as possible from the original source document to the data set, with as little interpretation as possible. The data transcriber should enter only what is in the original source document.
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e.g. "[Participant has 2 conflicting answers]" to indicate that these comments are **not** part of the original source.

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For the 3 months and 6 months survey collection

Every after 3 month period, the 3 month follow up survey will be administered again to the study participants partly to inform the CHW of the progress they are taking in terms of CVD knowledge, their attitude on appointment keeping with their health provider, adherence to medication, and their clinical measures (lower blood pressure reading).



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The SAME procedures will be followed for the 3 months and 6 months survey collection BUT the 3 month and the 6 month should not be administered by any CHW.