5.2 Appendix B: Participant information sheets (PIS)

5.2.1. Household Survey and Micro-costing study PIS

RESPOND

Responsive and Equitable Health Systems – Partnership on Non-communicable Diseases

We are conducting a research project to produce good information on the barriers to controlling high blood pressure faced by poor households in Malaysia and the Philippines. We are conducting a survey of households to seek adults with high blood pressure/hypertension and request to have interviews with them. Before you decide whether you want to participate, please read this information sheet carefully and feel free to ask any questions you may have.

The research project is being conducted by the Universiti Teknologi MARA (Malaysia), the University of the Philippines Manila College of Medicine, and the London School of Hygiene and Tropical Medicine, located in London, United Kingdom.

What is the purpose of the study?

The study aims to improve the management of high blood pressure in Malaysia and the Philippines and, in doing so, build capacity to address the increasing health and economic burden of non-communicable diseases (NCD), which now disproportionately affect low-income households in those countries.

Why is the study being done?

High blood pressure is one of the most important risks for heart disease and strokes. Nevertheless, a large percentage of individuals with high blood pressure are treated, but their disease is not under control and they are not always treated according to best practice. We need to fully understand what factors make optimal care possible, and which factors hinder such care. Eventually we would like to translate these findings into everyday practice. Taken as a whole, our study aims to improve the available services for diagnosing, treating and controlling high blood pressure. The study will provide a description of the way people with high blood pressure use the health care system and link this to overall health system characteristics.

We are interested in finding out about your experiences and opinions related to the management of high blood pressure, including about the treatment and care you have received, as well as your experiences of living with the condition, accessing healthcare and using services. We are interested in learning about the choices you make and the difficulties encounter in managing your high blood pressure, and how you try to overcome them. With this information, we would like to propose changes and recommendations that would improve how care for people with high blood pressure in the Philippines is provided.

What would I be asked to do?

In each selected household, we will ask for basic details of all members of your household, including age, sex, if any adults have been previously diagnosed by a health care professional with hypertension). If you agree to participate, we will take blood pressure measurements of all adults in the household aged 35 to 70 years using a simple, non-invasive monitor and if any of these adults have high blood pressure, then we will select one of them to participate in two interviews. The interviews will last no more than an hour each. One will take place today, if convenient, and another

one approximately one year later. The questions will focus on your experience of the health system for diagnosing, treating and controlling high blood pressure. You will not have to answer any questions that you do not want to and your responses will be made completely anonymous.

Is the research confidential?

Yes. No one will be able to identify you based on data that we publish. Any information that is shared will only be seen by the research team. All information collected in the interviews about you will be stored securely. Your name or any potentially identifiable information will not be used in any documentation related to this research project.

Who else is participating?

For this study we will be approaching 600 persons with hypertension residing in low-income communities as determined by various measures.

Will I be compensated for my time?

Yes. You will receive [REDACTED] for participating in this interview.

How will the research be used?

The findings of this study will be reported to all participating institutions and other parties interested in the Filipino health care system. The resulting papers will be publicised in appropriate domains where it will be available for use in guiding health care practice for future reform. The research will also strengthen capacity for health systems research in the Philippines.

After the project has ended, we intend to archive the survey data in the LSHTM Data Repository located in London, UK. The data may be re-used by other researchers doing other projects, for research and learning purposes. As this data will be fully anonymised before they are archived, neither any future researchers nor anyone learning about their work will be able to identify you. If you do not want your data to be archived, you do not have to consent to it and you can still take part in the study.

What are the benefits and risks of taking part?

You will be able to participate in a relevant research study that will help to improve the experiences of people using the Filipino health care system for hypertension diagnosis and treatment.

The interview questions asked are of a sensitive and personal nature, and it is up to you how much you decide to share. After discussing the health-related topics during the interview, you may have questions about your health, or you may feel you need healthcare services. We will provide you with a list of free or very low-cost services within your community that are able to answer any such questions and provide any required care.

Do I have to take part?

No, you do not have to take part in the study as participation is completely voluntary. You are free to decide if you want to take part in this study. If you do agree, you can still change your mind at any time and none of your data will be used. You can refuse to answer any specific question, or stop the interview at any point. You will not be affected in any way if you chose not to answer a question, stop the interview or not participate.

What happens next if I agree to participate?

You will be asked to sign the attached consent form, and the first interview will be scheduled at your convenience.

What happens after the interview?

After the interview, the research team will contact you approximately one year after the first interview to arrange for the second (and last) interview.

After conducting all the interviews, our researchers will analyse and write up their findings. A copy of the final report will be available to you after this date.

What will happen to information collected about me?

All information collected about you will be kept private. Anonymised data will be sent to study staff in London, and then back to study staff in the Philippines. This data will have your name and address removed so that you cannot be recognised.

What if I have any questions?

If you have any questions, you can ask them now, during the interview or later. If you wish to ask questions about our research project later, you may contact any of the following members of the study team:

[REDACTED]

This proposal has been reviewed and approved by the University of the Philippines Manila Research Ethics Board, which is a committee whose task is to make sure that research participants are protected from harm. To contact them, please call:

[REDACTED]

Thank you for reading this information sheet. Your help would be very valuable to us!