

## **INFORMATION SHEET FOR FOCUS GROUP DISCUSSION WITH PARTICIPANTS WITH LIMITED FAMILIARITY WITH DATA SHARING IN RESEARCH**

**Study Title:** Examining the views of stakeholders in lower and middle income settings on how public health research data should be shared.

### **Introduction**

Hello, my name is\_\_\_\_\_. I work with the Society for Nutrition, Education and Health Action (SNEHA) in Mumbai. As you are involved in research activities such as either collecting data or giving information to researchers I would like to invite you to participate in the study. It is important that you understand the information provided here, including what your participation will involve. Please give your consent to participate only if you have understood the study and are aware of your rights as a participant.

### **Who is carrying out this study?**

This study is being carried out by five groups and SNEHA is one of them, the others are in four countries: The KEMRI-Wellcome Trust Research Programme, Kenya, School of Applied Human Sciences, University of KwaZulu-Natal, South Africa, Mahidol University, Bangkok and Wellcome Trust Major Overseas Programme Oxford University Clinical Research Unit, Viet Nam. The study is funded by the Wellcome Trust and supported by The Ethox Centre, Nuffield Department of Public Health, University of Oxford.

### **What is this study about?**

When data is collected for research it is put in the computer, datasets are generated and analyzed, this information is used to write reports, papers, etc. Usually these datasets are available to the team or the organization which is involved in the research. However now there are international recommendations to make these datasets available to other researchers and/or organizations which may or may not be affiliated to those conducting the research. This is called data sharing in research. The logic for data sharing is that it will lead to faster analysis of datasets, save time and costs and improve the quality of analysis. The various issues that are associated with data sharing are of confidentiality, consent, advantages and disadvantages of data sharing, we would like to talk to you about these.

### **Specific objectives of the study include:**

- Understanding the views of the stakeholders about what they think will happen to their data and what are good data sharing practices.

- Identifying models of data sharing and governance currently in use and any issues they raise.
- Examining contextual factors affecting sharing processes.
- Identifying perceived principles of good practice in data sharing.
- Identifying suitable methods of developing appropriate data sharing processes

In this research, we want to learn more about people's views about the way that research is conducted by talking to people individually and in groups. We are particularly interested in learning about people's views on practices of data sharing within research.

### **Why do you want to talk to me and what does it involve?**

We would like you to take part in one to two discussions with [5-10] other persons with similar experiences. The discussion will be guided by one or two members from our research team. We will ask questions about your opinions on the way research should be conducted, and particularly about researchers sharing information from research. You do not need to discuss any topic you are not comfortable with. Only the people involved in the discussion, the person(s) asking the questions and/or a note-taker will be present. The discussion will be recorded unless any participant objects.

### **Are there any disadvantages or benefits to me of taking part?**

The discussions should take approximately an hour each. You will be provided with refreshments during this time and your fares to travel to the place where the discussions are held will be reimbursed.

We do not think that there will be any disadvantages of taking part, apart from the time taken in discussions.

### **Who will have access to the information I give?**

We will not share individual information about you or other participants with anyone beyond a few people who are closely concerned with the research. All of our documents and recordings are stored securely in locked cabinets and on password protected computers.

We would like to share the information that you give us with other researchers around the world who are looking at similar issues. Before we do that we would take any information that can identify you out of the document. We will also make sure the information is kept securely and that the researchers who want to access the data agree

to keep your data safe and private. We will discuss sharing information like this more during the focus group and you can decide about sharing your information after that.

We will ask everybody in the discussion to keep what is said in the focus group confidential, but it is important to recognize that we cannot stop participants sharing what they have heard.

Voice recordings made during this study will be deleted once the study is completed.

**What will happen if I refuse to participate?**

All participation in research is voluntary. You are free to decide if you want to take part or not. If you do agree you can change your mind at any time without any consequences.

**What if I have any questions?**

You are free to ask me any question about this research. If you have any further questions about the study, you are free to contact the research team using the contact below:

Anuja Jayaraman, Research Director, SNEHA on +91 9167749630 at any time during the study.

*[This study has been approved by the Mumbai Multi-Institutional Ethics Committee and the Ethics Committee at the Ethox Centre, Nuffield Department of Public Health, University of Oxford.]*