

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

Scenarios for FGDs

Nutrition cohort study

You may know that SNEHA is running a program in this area in which we are trying to find out if local community centres - SNEHA Centres - help to improve women's and children's health. You might also know that we are weighing all the children in the area every month to see if any of them are malnourished. If they are, we help them at daycare centres that provide extra food and other activities.

Malnutrition is a big problem in Mumbai and we want to find out how children become malnourished. At the moment, we're visiting every woman after she has a baby, and then visiting again every month to see how they're doing. When we visit them, we're asking about a number of things, and also weighing and measuring the baby. We're asking questions about families' background and possessions, water, toilets and electricity supply, other children in the family, pregnancy and birth care, family planning, the way mothers feed their babies, and any illnesses that babies might have. We're measuring the height and weight of the babies - along with several other measurements - and also asking about mental health and alcohol use.

The research aims to find out how babies grow in *bastis* like yours: why some children don't grow so well and become malnourished. When we put the information together we may be able to see patterns that could help us to think about what could be done to improve the situation and prevent malnutrition. This is what we want to do.

After we have collected the information, we put it all together and take away any facts that could link a particular person with it, like people's names and addresses. We will use it in the way I've described. But once it has all been put together we will have a lot of important information about the background and growth of babies in places like this *basti*.

It is quite possible that other people and/or other organizations would find this information interesting or important, even for reasons quite different from the original reason that we collected it from you. These people or organizations may include:

1. A PhD student from a university in Mumbai who requires this data to study the levels of malnutrition in *bastis* such as ours for her dissertation.
2. A team of researchers from America are interested in learning about the incidence and levels of malnutrition in urban India. They have asked many organizations like

SNEHA who work on malnutrition in Indian urban areas to share this data with them. They will compile this data into a huge dataset to understand and write papers and articles about this issue.

- What do you think about this sharing of the data?
- Are there any concerns about sharing this data?
- What are they?
- Why?
- What kind of data do you don't want us to share?
- What can we do to ensure that you don't have any concerns?

Tuberculosis

Tuberculosis (TB) is a major health problem in our city. It is an infectious disease which is transmitted through air and typically affects the lungs but can affect other sites as well. In November 2013, Tuberculosis Research Centre (TRC) had come to collect sputum from members (men, women and children) of your community in order to study the prevalence of TB in the community and to know what the characteristics of people who suffer from TB are.

In December 2013, TRC shared the results of the study with you. 400 community members are living with active TB. Overall, it was found that TB is higher among people infected with HIV and more common among men than women.

Now the World Health Organization wants to study TB resistant patterns all over India. Want to use the data collected by TRC to map the TB pattern for Mumbai.

- Do you think TRC should agree to give WHO access to this information?
- Why or why not?
- Is it okay for WHO to put the information on TB resistant patterns on a public website? All data will of course be anonymised.

Family Planning

You may have been part of many research activities conducted in SNEHA as well as conducted by other organizations. Say for example a study has been conducted with a group of women in this community or another community in Mumbai on family planning methods. We wanted to understand women's involvement in decision making on family planning methods such as decisions to use birth control pill or copper t or undergo surgery for sterilization after she has had the number of children she/family wished for

say one, two, four or six children.

Usually we interview women at their home but this time we asked the women to come to one of the SNEHA centres to be interviewed. Before starting the interview we took consent from the woman and told her that the information that she gives will be shared within the team and all the identifiers such as name, place of residence, etc. will be removed before sharing it with collaborative teams and from the report or paper so that she/they could not be traced back.

We start the interview after she has given consent. A rapport is built during the interview and she opens up and says, “I have three girls and do not wish to have any more children but my in-laws are pressuring me to plan another child as they want a baby boy. I am confused and rather fearful as we are financially not in a capacity to have more children and are not able to look after the girls and what if I have another girl child and not a boy....” So she starts to take birth control pills after talking to her doctor but has not told anyone at home neither does her doctor know that her family is unaware of it.

Few months later the project is completed we are out with our results.

After some time passes another independent organization approaches our organization with request to share this data that we have collected in the community.

- Do you think we can share this data with them?
- What according to you is sensitive data?
- What kinds of data can/cannot be shared?
- Consent process - What do you understand by consent and information sheet given to you prior to any study that is conducted with you all.
- Types of consent taken (broad, explicit, middle) and then in accordance share the data.
- Advantages
- Disadvantages

Violence against Women

Suppose an academic institution/university has received funding from international organization to study domestic violence against women. The researcher interviews women and some of them narrate incidences of being beaten or verbally abused by in-laws or by her intimate partner for various reasons. After completing their fieldwork the researcher analyses the data with his/her team and publishes results. Later another organization requests for the data.

Say for instance another academic institution/NPO/GO/Private institution requests for the data.

- Do you think the researcher can share this data?
- What are the roles, responsibilities and obligations of the researcher/research team/organization towards the participants?
- What are the criteria/ recommendations that you would like to put as stakeholders in research activities on the researcher/ team/organization before sharing the data?
- What do you think about this interview the data that would be shared with our collaborators and later archived and uploaded for open access?