

## **Guide 4 Annex 6: Example topics to explore stigma and mental wellbeing using qualitative methods**

To give you guidance in applying a qualitative approach, below are examples of topics you might choose to use in exploring each type of stigma.

### **Exploring stigma and mental wellbeing among persons affected by stigma**

- Internalised stigma

You can ask questions about whether having the disease has changed the participant's self-esteem or dignity and, if so, in what ways. In addition, it might be relevant if there have been changes over time and what triggered these changes. Feelings of fear, shame and guilt can be explored. A participant may, for example, feel to blame for their own health condition, thinking that they must have been leading a bad life and that they are being punished for it now.

- Depression

Depression often accompanies or results from internalised stigma. You can ask people who you think might suffer from depression whether they wonder if life is worth living and whether they have had suicidal ideas or plans. Hopelessness may play a central role in the way they feel. You can also ask about feeling sad and/or having a lack of energy to tackle their daily tasks. If people do express suicidal ideas, a plan should be in place to provide support or a referral to someone who can provide appropriate care.

- Anxiety

You can ask questions about whether someone feels as if something terrible is going to happen and asks to be reassured but is still worried. Ask them about physical symptoms as well: someone who has anxiety can experience heart palpitations and headaches and may feel that they can't breathe properly. Enquire about their sleep: do they sleep too much or not enough? How have these symptoms affected their life and ability to function as they would like?

- Mental wellbeing

Mental wellbeing is a broader concept than the presence or absence of depression and anxiety. Participants can be asked about how they feel in themselves more generally: whether they feel happy, whether they play a positive role in their family and their community. Being able to perform and be productive in one's job is also a sign of good mental wellbeing, as is feeling you have a fulfilling life and meaning. Wellbeing is best defined by people's own definition of what is important in life, so it is helpful to understand what they see as giving them a good life when you are seeking to understand their level of wellbeing.

- Perceived or anticipated stigma

People with a stigmatised health condition can fear that other people will react to them in a certain negative way. To avoid this negative reaction, people with a stigmatised health condition may change their own behaviour. Some of the NTDs that are stigmatised are concealable in their early stages, e.g., lymphoedema or Buruli ulcer. This may lead some people not to disclose that they are affected. For diseases with visible manifestations, this may cause people to withdraw from social interactions, for example avoiding places of

worship and public events and hiding in their own home. You can therefore ask about the changes in their life after being diagnosed with their disease and whether these changes had to do with fear of certain negative reactions.

- Experienced stigma

You can ask participants about the experience of negative reactions or actions by others because of their health condition (often called discrimination). Enquire about how it made participants feel, what specific emotions it triggered, what helped them cope with the experience. Did it have any impact on their ability to do things that they should be able to do in the same way as anyone else in the community?

- Dealing with different types of stigma/impact of different types of stigma



Photo credit: The Leprosy Mission Trust India

Are there changes in their social life, work or educational practices? What inspired those changes? How do people cope with their condition and the stigma? Participants may, for example, describe choosing to quit school or resign from a job out of fear of stigmatisation. They may also decide to conceal their condition to avoid stigmatisation, and as a result some carry the burden alone. Others might avoid hugging and kissing family members out of shame and perhaps the fear of contagion.

### **Exploring stigma among those who stigmatise**

You can ask people who do not have the health condition under investigation to what degree they feel, think or act negatively towards people with the disease or towards the disease itself. It may be that people are not aware of their negative attitudes until they are specifically confronted with examples. You can also ask whether they perceive or have indeed observed acts of stigmatisation in their environment. Be aware that people often know what they are supposed to say or realise that their real views might be unacceptable to you. You therefore need to ensure that they feel they can be honest and will not be judged, and what they say is confidential, otherwise your results will not reflect their real attitudes and beliefs, only what they feel you want to hear (this is called social desirability bias and is very important).

- Attitudes and beliefs of the respondent and others



NEGLECTED TROPICAL DISEASE  
NGO NETWORK

A global forum for nongovernmental organizations  
working together on NTDs



Photo credit: Wim van Brakel (NLR)

To explore attitudes and behaviour of people in the community or health workers, you can ask how the respondent views the health condition himself or herself, what ideas come to mind when hearing about the disease and what feelings the respondent has when thinking about the disease. Questions can be adjusted to ask about attitudes and beliefs of other members of their community, within their setting or facility. You can also ask how the respondent views people with the health condition under investigation. Do they think people with the health condition are in some way different? If so, how and why? How contagious are they? In the opinion of the respondent, are they in some way to blame for their disease? If so, how and why? Are they responsible for getting the disease? If so, how and why?

- Enacted stigma (discrimination)

You can ask the participant how people with the condition or disease are being treated in their environment. How do people in the community, a certain setting or facility react to people with the disease? Are they treated differently, and how or why?