Guide 4 Annex 3: Which instrument should you use?

There are several instruments to assess stigma. You first need to decide on the perspective that you want take: that of persons affected or that of community members, health workers, etc. You can then focus on a specific aspect of stigma, but if you want to get a more complete picture of the problem of stigma in your area, you will need to assess several aspects of stigma. This will require using several instruments. For example, measures of anticipated stigma, internalised stigma and experienced stigma are often combined. You can also use an instrument that comprises several sub-scales that measure different aspects, such as the SARI Stigma Scale. Flow chart 1 will help choose an appropriate instrument. There are many other instruments, especially condition-specific instruments, but those in the table have been well validated and have been shown to be suitable for use across conditions. In addition, these instruments do not require specialist training.

There are also several instruments to measure mental wellbeing or mental distress. You can measure mental wellbeing or mental distress in general, or specific conditions such as depression or anxiety. These are usually measured through different instruments. Although many other mental health conditions or aspects of mental wellbeing exist, this Guide will limit itself to methods and tools to assess the conditions and aspects mentioned above. Positive aspects, such as resilience, empowerment or self-esteem, can also be assessed and measured, but this is outside the scope of this Guide. Flow chart 2 will help choose an appropriate instrument. Again, there are many other instruments to assess aspects of mental health, but those in the table have been well validated, have been shown to be suitable for use across conditions and do not require specialist training in mental health.
Flow chart 1: choosing stigma assessment instruments

Who do you want to interview?

- Affected persons and their families
  - Perceived and experienced stigma
    - SARI Stigma Scale
    - EMIC-Affected Persons (EMIC-AP)
    - 5-Question Stigma Indicator – Affected Persons (5-QSI-AP)
  - Internalised stigma
    - SARI Stigma Scale
  - Social participation
    - Participation scale (P-scale)
    - Children’s Attitude Towards Illness Scale (CATIS)

- Community members, health workers, etc
  - Perceived attitudes and behaviour in the community
    - EMIC Community Stigma Scale
    - 5-Question Stigma Indicator – Community Stigma (5-QSI-CS)
  - Desired social distance (attitudes/fear) of respondent
    - Social Distance Scale (SDS)
Flow chart 2: choosing mental health assessment instruments

Persons affected by NTDs and their families

- Mental distress (including symptoms of depression, anxiety and medically unexplained complaints)
  - Self-Reporting Questionnaire (SRQ)

- Mental wellbeing
  - Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

- Depressive symptoms
  - Patient Health Questionnaire 9 items (PHQ-9)

- Anxiety
  - General Anxiety Disorder-7 (GAD-7)