

Report of the Research Workshop on Health-related Stigma and Discrimination

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Introduction

The impact of health-related stigma on the lives of affected individuals and their families has been known for a long time and has been well described, e.g. in the field of leprosy and mental health. More recently, the prominent role of stigma and discrimination in HIV/AIDS has become a major concern for those working with people living with this condition. Increasingly, the negative impact of stigma on disease control programmes themselves has been recognised and has led to calls for accelerated efforts to reduce stigma and discrimination. At the same time the lack of data on effectiveness of stigma reduction strategies and interventions has boosted work to develop new instruments to assess the various dimensions of stigma. However, such development work largely has been done within specific disciplines, such as HIV/AIDS, mental health and epilepsy.

The idea of pooling resources on stigma and discrimination evolved gradually after the realisation that interventions and theoretical stigma models within leprosy, mental health, HIV/AIDS and epilepsy showed many commonalities and following the successful development of a generic scale to measure participation restrictions in the fields of both leprosy and physical disability. Most articles on stigma and discrimination refer to the work of Goffman and many also to the dichotomy of felt and enacted stigma developed by Scambler. However, not much sharing of experiences between the disciplines is reported in the development of measurement tools and the development and implementation of stigma reduction interventions. We saw great potential in synthesizing all the work and experiences collected over the years in the various disciplines. By pooling research findings and experiences, it would be possible to find commonalities in stigma theories, measurements and interventions and identify disease, culture and situation-specific features. We hoped that by bringing all these experiences together common theory, measurements and interventions could be developed.

To start this process, the Royal Tropical Institute in Amsterdam (KIT) organised an international Workshop on Research on Health-related Stigma and Discrimination at the Kontakt der Kontinenten in Soesterberg, from 29 November to 2 December, 2004. The workshop was co-organised with the Swiss Tropical Institute and the London School of Hygiene & Tropical Medicine. More than seventy researchers and experts from the disciplines of leprosy, HIV/AIDS, tuberculosis, Buruli ulcer, mental health care, epilepsy and physical disability participated in the workshop. Together they represented 55 academic institutes, organisations and health projects in Europe, Africa, Asia, North and South America.

Before the workshop three background papers were written. Each background paper reflected one of the themes set out for the workshop; creating a model for health related stigma, establishing a methodological approach to measuring health related stigma and identifying effective interventions to help diminish health-related stigma. These papers were sent to the participants before the workshop to give an overview of the present knowledge within health-related stigma.

The workshop objectives were as follows:

- To review work done on stigma in the public health fields represented at the workshop, specifically to identify common crosscutting features of stigma, as well as distinctive disease- and culture-specific features.
- To identify gaps in our knowledge, including the magnitude of health-related stigma and discrimination in different countries and the determinants of these.
- To identify crosscutting features and differences in stigma experiences, models, assessment instruments and intervention strategies between health fields and cultures. To identify negative and any positive aspects of stigma.
- To draw together the common features of stigma in the relevant fields of public health and advance the development of an operationally useful concept and model of health-related stigma.
- To draw up a draft research strategy to develop, adapt and/or test instruments to assess key features of stigma and discrimination that may be applied for comparative study of health-related stigma within and across cultures and for impact evaluation of stigma reduction interventions.
- To identify crosscutting strategies and models of interventions for reducing health-related stigma at the local, community and national level.
- To develop an agenda for research and action, which may contribute to public health and social policy and to clinical practice.

A model of health-related stigma

Why study stigma? Stigma has an impact on the affected person by increasing personal suffering, affecting access to health care, and often also affecting human rights. Weiss, Scambler, Aggleton and Dijker presented their viewpoints on models of stigma. Stigma is a complex construct, is disease-specific, culture-specific and contributes to the 'hidden burden' of disease. In his paper 'health-related stigma: rethinking concepts and interventions', Weiss argued that stigma has become an important topic for public health. In doing so, health professionals should not only pay attention to the signs and symptoms of a disease, but also to the social aspects of illness. Although it is in the interest of public health to work to reduce stigma, a conceptual tension may exist between public health management of disease and stigma reduction. For example, exclusionary measures can be experienced as stigmatising, but is often based on rational public health control strategies. Weiss highlighted the importance of accounting for particular features of health-related stigma and the socio-cultural contexts that determines if a condition is stigmatised and that influences local manifestations of stigma.

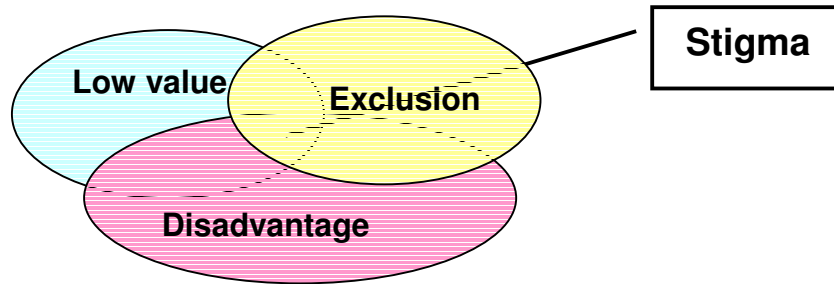
Scambler introduced the jigsaw model and argued that stigma is characterized by an ontological deficit combined with a perceived notion of culpability (for example, the assumption that someone living with HIV must have 'done something wrong' in order to become infected). Because stigma is a feature of social processes, it is important to note that often, those who are stigmatised are in part exploited, and in part oppressed, which is distinctly connected to relations of class and relations of command. Therefore, social structures are integral to a study of stigma. Stigma can be reduced by three different types of change, operational, political and structural. Operational changes can be achieved e.g., by health professionals within the health care system, political change requires action by governments, and structural change involves shifts at the level of social structures like relations of class, command, gender, ethnicity and age.

Aggleton argued that the concept of stigma has been overstretched, and, because of that, is at risk of becoming meaningless. Therefore, it is important to identify the domains of stigma relevant to health and to clarify that stigma is a process, not a thing. Stigma can be understood from a variety of perspectives, mainly, as enacted, perceived, and in addition, self-internalised stigma. Stigma reinforces pre-existing inequalities and social divisions present in societies, including those related to gender, class, race, etc. Therefore, we must tackle stigma at its deep-rooted sources, in a multidisciplinary, multi-sectoral fashion. There is a 'vicious cycle' of stigmatisation, beginning with a given marker of difference, which leads to stigma, discrimination, disadvantage, low self-esteem, and the worsening of the status, eventually leading to further stigmatisation. Breaking the cycle of stigmatisation at any of these points aides in the reduction of stigma.

Dijker explained that stigmatisation should be seen in relation to normal 'social control', that is, human response to difference. The human emotional response to difference can be either fight (which motivate anger/fear) or care (which motivates tenderness). Stigmatisation tends to occur when basic psychological mechanisms that originally allowed for adaptive forms of social control are activated under more complex conditions of living.

Report of Group I – Models of Stigma

After much discussion of where to begin in discussing models of stigma, this group came to the agreement that stigma exists where you have the intersection of social exclusion, disadvantage of some kind, and low value/low self-worth. We agreed that 'stigma' also exists with the intersection of any two of these three circumstances, all of which may be enacted by others, perceived as being enacted, anticipated, or self-imposed.



In subsequent meetings of the Models group, we expanded this model to illustrate that stigma is not an entity or thing that exists independently of society, culture, politics, etc. Instead, we looked at “antecedent factors” or underlying factors that contribute to the development of health-related stigma. We attempted to categorize these factors, using examples from different health problems. It was noted that different health problems or conditions, and certain treatment programs, create different (potential) stigma-related features. In addition, the same condition or feature of a condition might be perceived as stigmatising among some cultures/nationalities/ethnicities, but not others because of different “antecedent” conditions. Still, we were interested in seeing if there were some cross-cultural commonalities, at least in relation to particular health-conditions, or even across conditions, that could point to ways of addressing the problems of stigma. For example, it was discussed that for diseases that are already negatively stigmatised, such as leprosy, TB, and mental illness often (but not always), specialized medical centres for treatment of these conditions are themselves stigmatised, as are the patients that go to them. In this case, the antecedent factor would be the previously existing or historical stigma associated with certain diseases. Given this antecedent factor, the specialised treatment centre that is identifiable by others as a location for treating that condition constitutes a “stigma-related feature” of a specific condition.

Health problem	Focus	Underlying antecedent conditions and contexts contributing to vulnerability	Stigma-related features of specific conditions
Disease/ Condition/ Health Problem	Personal Impact		
	Health Service Use		
	Human rights		
	Other		

We ultimately developed a model that looks at factors that are not only “antecedent” or previously existing, but also at variables that may continue to interact with other variables to produce a certain type of stigma. We tried to identify as many of these variables as possible. They included:

- class structure
- social/cultural classifications of race, ethnicity, language
- global and local political economy
- history (this could include quite a bit: historical policies about the condition in question, historical factors that have shaped the position of different regions and nations in the world system, etc.)
- gender roles within a society (includes cultural expectations for behavior, appearance, dress, body type, marriage for men and women within a society)
- religion
- education
- occupation/job situations

- aspects of the medical encounter (structure of the healthcare system, access to healthcare, biomedical models of illness, treatment and side effects of treatment for the condition in question, etc.)
- conceptions of the body
- popular understandings of illness in general or of the condition in question specifically
- media representations (that reinforce or reflect cultural attitudes or that portray aspects of the health condition in question)
- behavioural norms
- conceptions about age

This list surely leaves out some variables. At the same time, some of the above overlap or could be grouped together under a single label, such as “culture,” “politics,” or “economics”; for example. Conceptions of the body may be determined by gender expectations, both of which might be considered aspects of culture, if culture is defined as learned behaviours and beliefs.

All of the variables above may interact with each other in a particular context. The way these variables interact with each other provides clues as to whether and how health-related stigma will exist within a society. This holistic model for looking at stigma is ultimately applicable to different health-related problems cross-culturally. As with other models of theory discussed by the group, it cannot be used as a predictor of stigma, but it can be used to understand stigma in context and thus formulate interventions that more completely address the roots of stigma.

Some of the papers presented in the Models of stigma group demonstrated that many researchers have already found ways to incorporate this model into intervention strategies. For example, Dr. Chowdhury presented his research and work with women and deliberate self-harm in Sunderban, West Bengal, India. These women were stigmatised and ostracized in their communities because they had attempted suicide. Mental illness, attempted suicide, and depression are all stigmatising in India, but he and his research team noted that the solution in this case lay not solely in trying to change societal attitudes about people who had engaged in deliberate self-harm. They also looked at the roots of the problem—why were women attempting suicide in the first place? Mental illness did not seem to be a cause of suicide attempts. Most of the women who attempted suicide were living with their husband’s family and reported being abused in the home. Laws such as the Dowry Prohibition Act, enacted to prevent spousal abuse or murder, have tended to create the opposite effect in some cases and increased abuse against women. The marginal position of women in general and particularly of the “daughter-in-law” in patrilocal rural Indian communities sets the stage for attempted suicide, which then creates stigma. Thus, educational intervention designed at eliminating stigma must be informed by a holistic understanding of where stigma originates. If interventions are constructed that deal with the root cause of stigma, which might be identified using the holistic model proposed in the models group, stigma may be eliminated as a problem.

Although the group did not move beyond the model to specific types of interventions that could come from the use of the model, we did discuss the importance of how information is presented in educational or media formats. Some noted that education does not always decrease stigma, and in some cases, those who are more familiar with the “facts” about a condition may be more likely to hold stigmatising attitudes. Again, the holistic model proposed would address this issue and could be used to help designers of educational material or social marketing campaigns be aware of how different variables may affect how messages are received.

Further issues and concerns include:

- We need to be cautious about confining our study of stigma to Western concepts of morality; shame and guilt may in fact not be cross-culturally relevant concepts.
- Proposed model for a definition of the experiences of stigma can be visualized as an overlap of exclusion, devaluation (low value) and disadvantage.
- Stigma is multi-layered, and any model or framework designed to address stigma must be able to address this complexity.
- Stigma occurs alongside other social realities and therefore we need to explore the interrelationships between stigma and these simultaneously occurring social factors.
- Is it ever justifiable to rationalize stigma caused by public health policy? Stigma is not a replacement for social policy and health policy.

- Legislation may not be responsive to reduction of stigma because of wider social and structural realities. Structural (operational and political) change must come first.
- Attention should be given to environmental and material, economic elements of stigma; if structural factors persist, the experiences of those affected may not change. We must be sure to involve people with stigmatising conditions in our work, and in further stages of development of the Consortium.

Methodological approach: measurement

van Brakel started off this theme with his keynote lecture 'Measuring health-related stigma'. To assess stigma and its determinants, a combination of qualitative methods (including in-depth interviews, FGDs, and observations) and quantitative methods (including indicators, scales, and questionnaires) methods are necessary. The complexity of stigma means that it is hard to pin down its nature to narrow, specific variables. Evaluation of change must involve the stigmatised, ideally asking them to identify felt dimensions of stigma before and after the program is put into place. Instruments to measure stigma and its related constructs have mostly been condition-specific. Approaches to stigma measurement have thus far focussed on the impact on the affected individual, perceived or felt stigma, self- or internalised stigma, the attitudes and practices of unaffected individuals, practices in health and social services, legislation, images of the affected as portrayed in the media and the public domain, and participation.

Measurement entails assessing the extent/magnitude of stigma, assessing change and measuring/understanding the nature of stigma. Development of a measure of stigma should be based on measures and scales that already exist.

Report of Group II – Measurement of Stigma

1. Stigma in the context of epilepsy, HIV/AIDS, TB, SARS and leprosy and the requirement for measuring tools.

The group heard presentations on stigma in the context of epilepsy, HIV/AIDS, TB, Buruli Ulcer, SARS and leprosy. These presentations drew attention to dimensions and domains of stigma that were common to many conditions. They emphasised the need for a better understanding of the nature and sources of stigma. A variety of qualitative and quantitative methods have been used to develop the existing tools, however, many of these have been used only once and most have been validated for use in only one condition. It is apparent that the demand for measurement tools comes from a great variety of conditions and contexts with the further complication of cross-cultural comparisons. Discussion focussed on what is required of a tool, what is to be measured and the tools already available.

What is required

Measures of stigma will be required to assess extent or magnitude, to allow broad comparisons, to reflect the nature of stigma, to assess change and to describe what is going on, for example, interpreting responses to the recent SARS outbreak as the outworking of stigmatising attitudes. Tools must be fit for the purpose and must cover all dimensions subject to change. They must be developed through qualitative as well as quantitative methods.

What to measure

Measurements are needed for all forms of stigma, experience (enacted), perceived and internalised. They need to cover all dimensions such as knowledge, values, attitudes and social distancing and life domains such as family, work and education.

What is already available

The group acknowledged the substantial implications of developing a new scale and recognised the value of focussing on existing proven tools in order to identify tools that may be further developed and validated to assess domains not adequately covered. The group also discussed the value of developing a database of existing domains, tools and items. Other issues relating to the choice of measurement tool include the model or understanding of stigma and the form of intervention.

2. Requirements of any new scale

Fundamental to the preparation of a new scale is theoretical underpinning. There must also be a clear understanding of the purpose of the scale. Specific scales may be needed to measure response to an

intervention. Measuring stigma in the community is not the same as measuring stigma in the individual and raises issues about the aspects of stigma to be measured. Measuring change is problematic for a number of reasons. First it is important to understand the changes that are expected. Next, there is the question of how to measure the specific change that is of interest and the minimal set of questions that will provide the necessary information. Finally there is the question as to whether a small change in a score reflects a real change in the individual's life.

Domains measured in HIV/AIDS stigma

In the context of HIV, current tools assessing stigma in affected communities and stigma experienced by people living with HIV/AIDS address the following domains:

Domains for communities affected by HIV	Domains for people living with HIV
HIV knowledge and casual transmission	Perceptions/fears of what would happen if become known
Questions relating fears to actions	Actual stigma experienced:
Values and attitudes	Denial of rights
Issues of responsibility or blame	Exclusion by family
Social distancing	Loss of respect, social status.
Willingness to interact with affected people	Ridiculed, hassled, threatened, assaulted
Support for coercive measures	
For example, quarantine	

Domains currently not measured in the context of HIV/AIDS include enacted (experienced) stigma at the population level, which has proved too difficult to address directly. Few studies document experience. Compounded or layered stigma as experienced by individuals stigmatised because of sexual orientation, drug use or role as a sex worker in addition to their HIV status has also proved problematic.

3. Gaps and Challenges – the focus for future research

In summary, the challenge is to identify tools that will assess the extent of stigma, the nature and determinants of stigma and changes in stigma. Equivalent tools are needed in the context of enacted, perceived or felt stigma and self or internalised stigma. These requirements are interrelated and must be developed in the context of a comprehensive model of stigma.

Dimensions of stigma

The group identified three dimensions of stigma. **Felt or perceived stigma** includes the individual's perceptions and fears of what would happen if their status became known. **Enacted or experienced stigma** includes denial of rights (healthcare, employment, housing), exclusion by family and community, loss of respect or social status, verbal and physical abuse. **Self- or internalised stigma** consists of negative self-image, expression of shame and guilt, self-isolation, withdrawal including negative self-image, feelings of uncleanness, expression of shame and guilt. More work is needed to relate this understanding of stigma to earlier models that located fear and shame (i.e. internalised stigma) within perceived or felt stigma.

Filling gaps

Discussion identified the following research questions related to maximising the use of existing tools and filling gaps in existing knowledge.

- Which existing measures may be refined and validated for wider use?
- What are the fundamental causes of stigmatising actions, is there an alternative to asking hypothetical questions, so overcoming problems of ambiguity?
- How can we best measure different dimensions of stigma (enacted, perceived, internalised)?
- Which of the identified dimensions are amenable to assessment with a generic instrument across cultures?
- What are the key domains currently without measurement and how may they be addressed?
- How do we access those affected – for example, those who do not know they are already HIV positive?
- What are the gender-specific items that differentiate the experience of men or women?

- What is extent/nature of stigma for children? How can we best measure stigma across the life span – e.g. for children versus adults?
- How do we measure people's understanding of Human Rights related to discrimination and stigmatisation?
- How do we measure coping, resilience and management skills in relation to stigma?
- How do we measure averted (prevented) stigma?
- How do we measure challenging/confronting stigma?

Development of stigma indicators

Currently three groups are working in Tanzania. There is a need to field test indicators and to measure specific domains and constructs of stigma. Most indicators used to date give skewed data, positive rates of the order of just 10%. There is always underreporting of stigma, suggesting that more research is needed, for example, to explore the difference between what people say and what they do. How does one measure gossip? Does gossip reflect real attitudes and affect subsequent behaviour? If people's behaviour is affected by gossip then this is an important point to consider in selecting and preparing interventions and indicators.

In what way would it help us to find out what motivates behaviour? For instance, how do we find out if one person does not want to eat with another out of fear or out of shame. These questions concern deeper knowledge. Would a better understanding help us to develop better interventions and indicators and to assess impact?

Potential indicators of what people fear in relation to stigma have been identified as follows:

- | | |
|------------------------------------|---------------------------|
| • Exclusion from social gatherings | • Abandoned by family |
| • No longer visited | • Isolated in household |
| • People 'check them out' | • Lost customers |
| • Lost respect | • Denied promotion |
| • Abandoned by spouse | • Denied religious rights |
| • Teased or sworn at | • Had property taken away |
| • Gossiped about | • Sent home to village |

Methodological issues

The following issues were identified in relation to methodology

- What methods are most effective in measuring change?
- What is the best set of answer choices in a quantitative instrument – e.g. Yes/No, Likert scale?
- In the context of evaluating interventions, what is the minimum requirement for validation – for example in the use of a combination of methods and sources?
- Importance of informed consent
- Consciously and explicitly express ethical issues in health-related stigma research, specifically:
 - Interviewer training – sensitivity, skills, and awareness of unintended consequences for interviewer and interviewee
 - Appropriate response mechanisms including referral arrangements

Focus Group Discussions are used to guide content and identify issues. However, scales based on a small and manageable set of questions may lack cross-cultural applicability.

Strategic Issues

The group identified approaches that would maximise the value of any future research. These included the following:

- Address health-related stigma in multiple conditions - collaborate across diseases, programmes and disciplines to maximise the use of resources.
- Need to demonstrate links between stigma reduction and health-related outcomes or quality of life
- Frame research in terms that are relevant to decision-makers, policy makers and funding agencies
- Emphasise the value of a single, basic quantitative measure applicable to and validated across wide-ranging contexts and conditions

- Involve communities in the development of methodologies and instruments

Other proposals

The group identified the need for continued communication and networking through all available means. Collating information on indicators used within existing tools would be a valuable groundwork that would benefit any future research. The same would be true of peer reviews of available tools and instruments. This may be an appropriate activity for a PhD student. Such activities may extend to developing a database of items or questions from existing scales and tools. Informal discussions may identify opportunities for research collaborations within either existing or new research projects.

Further issues and concerns regarding measuring stigma include:

- The importance of using people who are suffering from the conditions themselves in all stages of stigma study.
- There is to be aware that research methods may risk reinforcing stigma by the way in which the respondents are queried.
- Need to work across different settings in which stigma can arise in a given cultural context (household, workplace, etc.)
- Limitations of a stigma scale for understanding stigma; triangulation is important to capture variability and complexity of stigma within and across groups and may not be able to capture social processes.
- What do we know about stigmatisers? How do they stigmatise and why?
- Ethical considerations should be central to research on stigma because the issue is so sensitive that when we research stigma we are in a position to do great harm.
- It could be useful to borrow from studies done on bullying amongst children and children of psychiatric patients to understand the impact of stigma on behaviour.

Interventions for stigma reduction

The discussion on the experiences with stigma reduction interventions and their effectiveness was started off with three lectures. Sartorius reported of his 10-years experience with the WPA programme and presented a list of key decisions concerning intervention planning and implementation. He also explained that knowledge about a health problem does not necessarily lessen stigma, but can rather lead to greater fear and decreased tolerance. Mwambo presented experiences gained in the HIV/AIDS field. She too showed how knowledge can increase the fear of the disease. Care and support of the ill exist, but they coexist with stigma. Empowerment of the affected can reduce stigma among the affected, turning anger into action and creating solidarity among those who go public with their disease and normalization among unaffected public. She argued that people are often unaware of their stigmatising behaviour. Birbeck gave a short report of the experiences of stigma in the field of epilepsy and emphasized the importance of understanding the mediators of stigma.

Report of Group III – Stigma reduction interventions

Members of the “interventions” group were tasked with comparing their experience of stigma and examples of interventions in diverse cultural settings and social environments. The examples discussed came from experience with conditions such as Buruli Ulcer, leprosy, tuberculosis, HIV and AIDS, mental illness, epilepsy, disability and other chronic diseases from geographical settings in Asia, Africa and Europe.

Identity and normality

The group discussed the concept of identity, that people had a strong desire to stay “normal” and be seen as “normal” so that they could carry on a functional life and not be separated from their peers and community. Included in this were:

- Getting married, having children, continuing at work despite their illness, even if it was life threatening such as in the case of AIDS.
- Denial of symptoms even when they were obvious to others
- Delay in health seeking behaviour since this was an acknowledgement of having a problem
- Fear of deformity or disfigurement since these were the “stigmata” that labelled them as afflicted
- Refusing to accept help from able-bodied people or offers of support being seen as patronising.

Fear

Fear within communities against people affected by certain conditions is often based on a fear of contagion, even associated with non-infectious conditions, and needs more understanding. If the disease leaves deformity such as blindness or scarring, the fear of contagion continues after cure. Fear of a chronic infection such as leprosy or tuberculosis in earlier stages may persist even after control has been established. Knowledge of modes of transmission does not necessarily reduce fear, and sometimes may increase it. The fear is often more of contamination, whereby association with a stigmatised person brings the stigma onto oneself, the person rather than the disease being seen as dangerous. Fear may be related to possible violence, unpredictability or inappropriateness of behaviour, such as with mental illness or epilepsy, where the origin of the behaviour is not understood and attributed to bewitchment or evil spirits. Sometimes, the stigma is transient and may disappear after the condition is medically cured such as with TB. When there are long asymptomatic periods, for example with HIV and hepatitis B, stigma may come and go. Attitudes may change over time especially with access to treatment. Cancer used to carry stigma associated with death that has improved in many countries. Mostly though, stigmatised conditions are trapped in a chronic disease box, with social chronicity outrunning biological chronicity.

Self-stigmatisation is usually associated with fear of abandonment: marital, community, workplace, church. This is not an unrealistic fear, since many do indeed suffer from rejection at all levels. When conditions are thought to be hereditary there is fear that family members will be rejected in marriage, even if they are not directly affected by the condition. Aspects of shame, blame, guilt, inner pain all attach to the condition and those affected. The sense of poor self-worth associated with self-

stigmatisation is reinforced by the rejection of the people around them. However people with the condition may attribute incidents to the condition when in fact they may have no relationship to it.

Negative stereotyping

Surveys show that large numbers of disabled people feel discriminated against. The feeling of “badness” is often internalised by families who either exploit their earning potential as beggars or reject them. They may have to work as beggars because of being excluded from labour markets or being rejected from their family homes. The presentation of disability as victimhood may mean that people’s potential and skills are not utilised and that they are seen as incapable of contributing to family income or communal good. Problems are attributed to the disability when in fact they may be shared by able-bodied also, such as unemployment or poor education. When people with disability are always seen as beneficiaries or victims, their strengths are not recognised and approaches, for instance by health staff, may be paternalistic. These attitudes apply to most stigmatised conditions but are exemplified by physical disability. People with these conditions want autonomy, to do things for themselves, with partnership and solidarity from supporters rather than pity.

Marginalization

Families became stigmatised by the condition of a parent or child, even if other members were healthy, through the fear of their communities of the condition. So families were affected by the physical impact of the condition, and then also by the effect of the stigma created by the condition. We discussed whether this fear was rational, some group members feeling that this was mainly due to the fear of contagion, while others felt it was also fear of difference.

Many of the conditions discussed increased poverty through loss of work and earnings, especially if there was severe disability involved, and through loss of support from their communities. Families from marginalized groups experienced layering of stigma, whereby they were more vulnerable to ill health through poor access to health services, more vulnerable to the impact of the condition through their poverty, and more vulnerable to the impact of the loss of support from their community. In this way, poverty and disadvantage were worsened by the condition and by the stigma associated with it, with downward social drift of affected people as a result. As a survival tactic, some families would abandon their affected relatives as a way of preserving most of the family, sacrificing the others. Affected people may also take themselves out of “normal” society to avoid infecting or affecting others. This is perceived as responsible behaviour but may reinforce a sense that these people must be kept separate, even when they are no longer infectious or showing inappropriate behaviour in the case of mental illness.

Those with higher status in society, with more economic power, enhanced self-esteem and confidence, popularity, better access to health care and privacy especially through payment for services, suffered less from the impact of stigma associated with their condition. They are able to be more vocal and see themselves as deserving of rights to benefits rather than charity. Key aspects of surviving stigma were being treated with respect and dignity. The response of gay men in affluent communities such as the USA and Europe provided one example. Despite the stigma associated with homosexuality, many gay men organised together to push for funding for research for treatment of HIV-related conditions and refused to be belittled or shamed. Disabled people with facility to buy equipment, adapt vehicles and accommodation to suit their needs, get individualised prostheses and so on, were in better positions to lead functional lives including competing in sports, giving themselves better self worth.

Human rights

People suffering from stigmatised conditions are often denied basic human rights such as access to health services, work, housing, education, because they do not have the power or support to fight for them. Sometimes ignorance of modes of transmission of communicable diseases underlies denial of work or education facilities. Often it is a sense of poor value that restricts participation. Legislation to protect the rights of people with disability or being treated for a chronic illness, is important to establish the principle. However, the fear of discrimination may prevent disclosure of illness, even when there are rights and benefits reserved. The Treatment Action Campaign in South Africa laid down the principle that people with HIV had the human right to treatment under the constitution of the country. By marching through the streets wearing T-shirts proclaiming HIV positive, emphasising positive in attitude as well serostatus, participants were making a statement that they were not

ashamed of their status, that they valued themselves and deserved the same rights as anyone else with a life threatening illness, to be treated with respect.

In conflict situations and wars, women who are raped may get pregnant or infected with sexually transmitted infections, but the blame of “being spoiled” attaches to them and their children rather than the perpetrators. Refugees and displaced populations also lose their pride and identity through having to leave their homes and may be looked down upon by the host country residents.

Belief systems and influence of religion

Religious beliefs often proscribed attitudes towards people with stigmatised conditions. These could be supportive or negative towards them. For example people with leprosy were told by the bible to live and dress in ways that separated them from others, to ring a bell to warn people away when they approached. Many religions saw disease as punishment from God or warnings from ancestral spirits but appeasements could be made that helped families to cope, deferred responsibility and defined relationships and behaviour within communities. Individuals who breached societal rules for instance through extramarital sex, could come back into the fold after performing rituals designed by traditional healers. Traditional practitioners prescribed herbal remedies that fitted with their belief systems and were more acceptable. However, these also delayed the time of seeking medical help for their condition. Traditional societies are often seen as more supportive of people with disability through acceptance that each person has a place and contribution to make. At the same time, causes of feared diseases were often attributed to “witchcraft” or poor hygiene.

Examples were given of religions being condemning, judgemental, supportive and compassionate in different contexts. Some faith-based organisations condemn HIV as a product of immorality that taints whole families regardless of their behaviour, thus depriving them of support. At the same time, priests in Uganda have been inspirational in being open about their HIV positive status, providing role models to others. Many health services for chronic diseases are provided by religious groups and missions, but with segregated facilities that increased a sense of separateness. Faith is supposed to give hope, but makes judgements of what is deserving. Sometimes intolerance outweighed attempts to reduce stigma.

An example was given of a stigma reduction toolkit through which faith leaders who were encouraged to take responsibility for stigma, left the meeting feeling emotionally engaged and asking for forgiveness for their previous responses.

Iatrogenic stigma

Sometimes there was conflict between health education given for prevention or to encourage early presentation to health services, for instance by teaching signs and symptoms of diseases, and the fear created by identifying people with these. This was referred to as iatrogenic stigma, where health professionals make stigma worse in their efforts to educate communities about such conditions. Resource constraints, insufficient training, poor supervision, low professionalism and stress inherent in public sector health and social services often leads to inadequate care given to patients. Health workers become stigmatised by association with working with stigmatised patients, making it harder to work for such programmes. Staff may be fearful of the conditions they are dealing with even when they are familiar with relevant biomedical aspects. They sometimes do not offer diagnostic procedures because they themselves feel it is “better not to know”. Alternatively, treating patients and clients in dismissive ways would discourage them from attending for health care in time.

Interventions

The group agreed that there are several models of good practice that can be learnt from, by looking at what has been successful in other fields such as behaviour change. Often programmes are not designed to challenge stigma, but this results as a by-product of the “culture” of the intervention. Communities are at different stages in their response to stigma for various conditions, so a range of interventions is needed that are responsive and appropriate to the context we are working in, rather than seeking universal answers. Programmes have the best chance of success if they are multifaceted, multi-layered and multidisciplinary.

The categories of operational, political and structural dimensions to stigma are important to establish what is needed in each intervention. Questions we discussed were:

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- How to provide skills for employment in high unemployment environments – to avoid setting people up to fail or have unrealistic expectations
- Providing benefits through programmes can create privilege leading to resentment from others [reverse stigma], for example when school fees are paid for one group and not another

Since we are dealing with complex behaviours, societal values and attitudes that may take decades to change, studies need realistic long-term funding to enable longitudinal rather than cross sectional research with validated measures of stigma reduction. Services deserve the same priority in funding as other chronic diseases such as hypertension and diabetes. Successful integration into national programmes may be more sustainable than project work dependent on external funding. However, evidence of successful practices from project work is often not transferable to the public sector because they are less resourced and staff are not as dedicated. Public sector funding in developing countries is usually lower on a per capita basis than non-governmental organisations that may have access to international funding.

There was concern that programmes in the past have inadvertently endorsed paternalistic approaches to people with stigmatised conditions. This must be addressed by working with affected groups as partners, rather than in a tokenistic way. There is currently more evidence on how to do this from programmes that have active participation of the beneficiaries. They should be involved from the outset in the design and development of research activities, so that they define the priorities addressed, own the outcomes of the work and the implementation of the interventions developed. Advocacy and activism are enabling functions that emphasise solidarity and community action rather than isolation and victimhood. The more organised and proactive the affected group, the quicker the response of communities, funding agencies and government bodies. There is currently more evidence than before on the success of skills transfer, coping strategies, psychosocial support, support groups, community mobilisation and networking and social skills training leading to more autonomy, confidence, self-efficacy, self esteem for participants.

Interventions need to be driven by theoretical frameworks, as with the STEP [stigma elimination programme] in Nepal where the focus was on transforming individuals from having spoiled identities to becoming change agents for their communities, being taught facilitation skills to enable community members to have more education and independence, learning to open bank accounts and so on. There needs to be more understanding why educating communities fails to reduce stigma and discrimination. What people do is frequently different from what they say, so there is a need for validation of findings through different interventions and methods.

The targets of interventions would be everyone, at all levels of communities but especially using knowledge of change management theories to target those who are influential and have leadership roles such as faith leaders, policy makers, legislators, police. Families are often mediators of stigma as well as recipients and multipliers, as are health workers despite working closely with their client groups. Education on the negative impact of stigma may assist those who are unaware that they are showing stigma to understand the consequences of their actions. This is particularly true of health workers and other public service providers. Methods shown to support public service workers to overcome their prejudices need dissemination such as values appraisal for health workers evaluated by the WHO. Faith-based institutions are a good entry point for stigma reduction, tolerance and acceptance especially through their outreach programmes such as home based care. The example of the stigma reduction toolkit used with faith leaders could be used more widely.

Monitoring and evaluation

Health impact assessment at the design stage of project development may be used to anticipate how programmes could potentially make stigma worse, and build in defences against this such as though advocacy led by affected people. Methods of monitoring and evaluation need to be built in from the outset with flexibility in programmes to make adjustments as needed. Participatory methods that include users of services and programmes would improve ownership of activities.

Indicators that can be used to detect stigma reduction are:

- Improved community diagnosis and case-finding
- Earlier presentation with symptoms
- Increased uptake of health and social services

- Increased awareness and uptake of benefits such as housing, schooling, welfare payments
- Measures of autonomy and independence such as getting through employment interviews, opening bank accounts, staying in work
- Ability to live in integrated housing in community
- Volunteer support provided by community
- Existence of support groups that are attended by members
- Existence of income generating projects that provide social support, networking as well as providing financial support

The group identified some guiding principles that should be taken into account in creating interventions, these are:

1. Start with local strengths.
2. Incorporate the cultural context.
3. Include participation from persons with the condition at the in all stages of intervention development.
4. Multi-level interventions (individual/ community/ societal etc)
5. Take gender issues into account.
6. Be careful of group/individual status.
7. Be sensitive to existing groups/needs; develop approaches based on the individual/group needs and continue follow-up.
8. Use Human rights approach
9. Use age-specific approaches (L).
10. Use family, extended family approaches (HIV).
11. Interventions should be on-going and sustainable.
12. Promote positive images and success stories.
13. Learn from and use best practices/lesson learned.

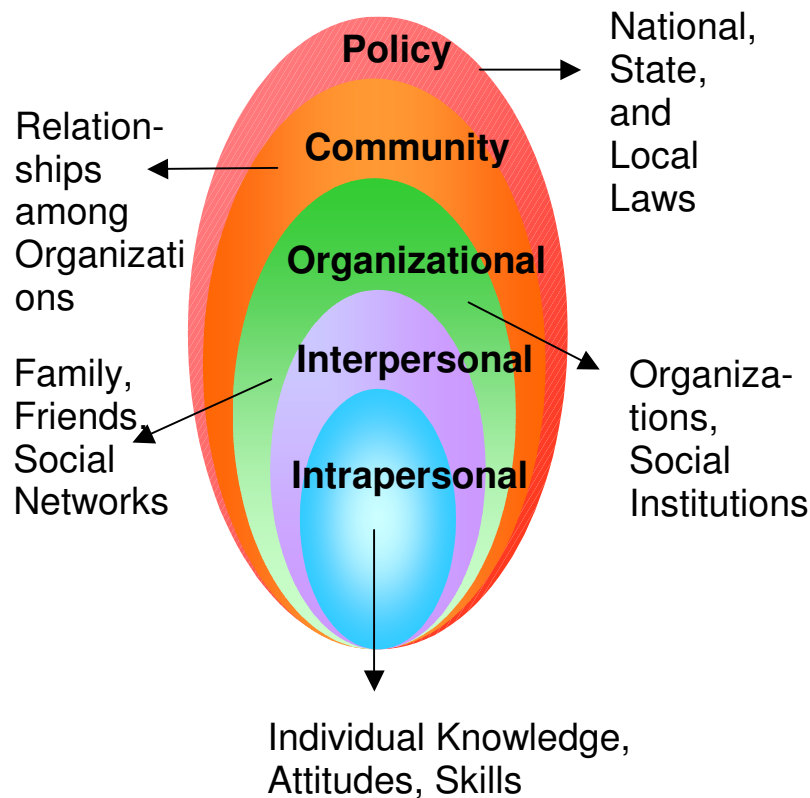
The guiding principles are summarised in a process cycle (see appendix 2).

The deliberations of the group established the context of many dimensions of stigma that we are working with, accompanied by direct experience of interventions we were familiar with. From this a list of potential interventions and target groups was drawn up.

I. Levels of Intervention¹:

- Intrapersonal/Individual
- Interpersonal
- Organizational/Institutional
- Community
- Policy/Societal
- Global (an addition of the intervention working group)

¹ Source: McLeroy KR, Bibeau D, Steckler A, Glanz K. An ecological perspective on health promotion programs. Health Educ Q. 1988 Winter;15(4):351-77.



Appendix 3 gives an overview of examples of interventions at these different levels.

II. Target Audiences for Interventions

- People who are stigmatised
- People who do the stigmatisation

Further issues and concerns regarding the stigma reduction intervention include:

- What sustains stigma?
- How to evaluate the psychosocial process of stigma?
- Why are some societies more tolerant of difference than others?
- We should be aware of intervention approaches that have worked and why, so as not to repeat our mistakes.
- If we knew more about how and why people stigmatise, appropriate interventions would be clearer. Who is excluding whom and why?
- Output from this workshop should be sent to the groups of those affected by the diseases concerned.
- We should be cautious not to label someone as stigmatised; let us not start with the assumption that all people are feeling stigmatised.
- Experiences with stigma work and interventions are often found in the 'grey-literature' (i.e., list-serves, etc.), for communicating on this work; this group can help to validate these studies and publication.
- How do deal with stigma in the context of conflict situations, among refugees, who may be blamed for their situation?
- In what way do health workers perpetuate fear and stigma?
- We must ensure that stigma reduction programmes do not create privilege for some and in so doing, create resentment from others (for example, paying school fees for some affected children may create resentment from other community members).

Conclusions

Social exclusion and discrimination due to particular health condition are major hindrances for both patients and healthcare. This applies to people affected by leprosy, tuberculosis and HIV/AIDS, as well as to those with chronic health conditions such as schizophrenia, epilepsy and physical disability. A major finding of the international Workshop on Research on Health-related Stigma and Discrimination was that social and societal consequences of stigma and discrimination are very similar across the different healthcare disciplines as well as across different countries and cultures. For example, problems relating to marriage, (family) relations, work and education appeared to be practically universal. Much similarity was also found in the very negative impact of stigma on public health activities, such as combating HIV/AIDS, leprosy and tuberculosis. For instance, many people who may be HIV-positive are extremely reluctant to undergo testing, to cooperate with prevention or to accept treatment, because of the possible social consequences of disclosure of their status. In leprosy and tuberculosis control programmes, the fear of stigma is often a reason that people are very slow in coming forward for treatment. Stigma and the fear of discrimination can adversely affect adherence to therapy. Dealing with stigma and discrimination is now a recognised priority in each of the above-named healthcare areas.

Stigma models

It was concluded that a model of stigma must include a conceptual basis that reflects the complex influences and dynamics of the antecedent social conditions that underscore the occurrence of stigma. These antecedent conditions include factors such as gender, religion, economy, history, class, race, politics, health services, etc. A model of stigma must also capture the condition-specific features of stigma, including the factors leading to a particular condition being stigmatised, its personal impact, impact on society and the impact on public health services.

While we seek to capitalise on the cross-cutting features of stigma and its impact, we cannot ignore existing differences between conditions and cultures. When designing stigma reduction interventions and attempting to measure stigma, these differences should be taken into account.

Stigma measurement

When measuring stigma, the specific purpose of the assessment and the questions to be answered must be carefully considered and the instruments used must be chosen or designed to match these. Sample research questions include: Can perceived stigma be measured separately from self- or internalised stigma? How to measure resilience? How to identify varying dimensions of stigma across cultural contexts? Is there an agreed standard for validation? How to best measure change over time? How do we measure compounded stigma or layered stigma?

Research on health-related stigma should be directly relevant to policy and funding, at the same time attempting to increase our scientific understanding of the phenomenon. Assessment instruments should create a link between stigma reduction and health-related outcomes or quality of life. The tools should enable assessment of the extent (severity) of stigma, improve understanding of the nature of stigma and allow assessment of change in stigma. A combination of qualitative and quantitative methodologies should be used. Although all indicators and instruments measuring stigma may not be applicable across settings and diseases, a core set of indicators/measures that are applicable across settings/diseases should be identified. To ensure that local priority and relevance is taken into account, communities should be involved in the creation of the measurement instrument and/or indicators.

Stigma interventions

Stigma can be reduced by addressing the health problem, the stigmatisers, the emotional impact, or by creating effective social policy. Social solidarity created through social networks, such as in self-help organisations, can reduce stigma. Approaches to stigma reduction can be built upon wide perceptions of social injustice which can motivate people towards action, networks of communication and community trust. Stigma reduction must be established through existing structures in society rather than put into place externally. Interventions for stigma reduction should be aimed at the various levels where stigma occurs.

Although much has been done at the individual level to decrease health-related stigma, much less has been done at the community, society, institutional, and global levels. A multi-sectoral approach is

needed, using common strategies across disciplines. The role of belief systems in coping should be better understood. The role of the family as mitigators of stigma and ways to include religious organizations as motivators to encourage ideas of socially responsible ways of behaving should be investigated.

Interventions should take into account the determinants of stigma, such as the difference between stigma associated with chronic and with transient conditions. Some stigmatising conditions may move the afflicted in and out of the so-called 'normal' identity upon being cured of their disease. Some individuals with power and status may be better equipped to overcome and override the effects of stigma, underscoring the fact that stigma is worsened by pre-existing marginalisation, but can be overcome by enhanced social standing, support, and understanding.

All interventions must build on local strengths and resources and embed actions within the local cultural context. We must try to understand those features that enable some to be more resilient to stigma. We can learn from what has worked for some groups; for example, highly active, vocal, and organized groups, such as the Disability Movement that succeeded in bringing about many structural changes for the benefit of people with disability, as well as a considerable improvement in social inclusion. Another example is that of the Gay Men's Health Crises and other gay activist groups during the initial phases of the U.S. HIV/AIDS epidemic, who brought the issue to the fore and subsequently began to work to de-stigmatize it. We must understand and anticipate how programmes can make stigma worse by adding information but increasing fear; public health interest may not always coincide with interests of stigma reduction. Therefore, a careful analysis of the costs and benefits must be performed. Like in the example of the gay activists in the early phases of the HIV/AIDS epidemic, advocacy, design, and implementation of stigma reduction programmes must be led by the affected. This would increase the chances of success of the programme. Monitoring must be established from the beginning of the programme to ensure that it is reflexive and responsive to changing needs.

A new international consortium on stigma research and action

Recognising the similarities in the experiences and consequences of stigma provides a basis for a common approach, particularly in terms of collaborative research. It is hoped that this will result in improved strategies to mitigate (the effects of) stigma, applicable to all healthcare disciplines. A new international consortium for research on health-related stigma has been established to strengthen collaboration and the exchange of knowledge and research results among the various disciplines. The name of the consortium is International Consortium for Research and Action Against health-related Stigma (ICRAAS); website: www.dgroups.org/groups/Stigmaconsortium. See appendix 4 for the consortium's 'status and functions' document.

Sponsors

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Appendix 1 Potential indicators of stigma

The below inventory, made by the Measurement group, related only to enacted stigma / discrimination. A similar exercise should be conducted for the other dimensions also.

Indicators for institutional discrimination	Conditions that report exclusion
Health Services	
Denied access to (general) health services	H, L, S, T, M,
Referral within health services	H, S, T?, E?, L, MH, B, CD
Reduced quality of service	
Educational context	
Denied access to education	H, S, T?, E, L, PD, MH, CD
Children of affected people denied access to education	H, S, T, E?, L,
Work Place	
Refused appointment/recruitment	H, S, E, L, D(?), MH, B,
Relating to promotion or skills development	H, E, L, MH, CD
Fired from job	H, S, T, E, L, D, MH, B?, CD

Leprosy (L), SARS(S), Buruli Ulcer(B), TB(T), HIV(H), Epilepsy(E), Mental Health(MH), Cognitive Disability (CD), Physical disability (D)

“?” signifies uncertainty

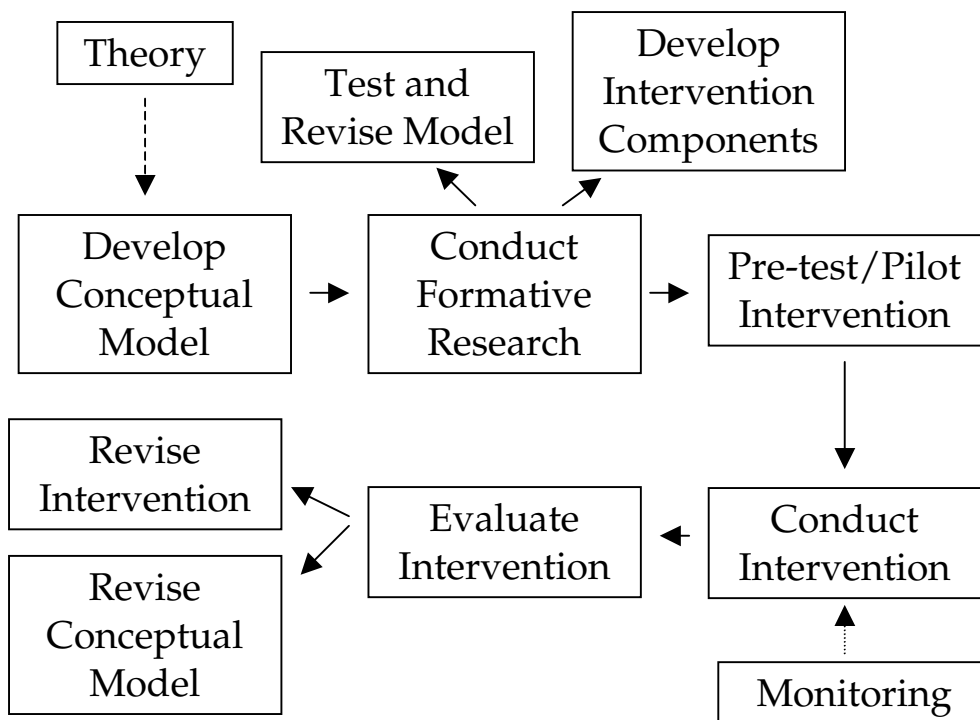
Indicators for interpersonal discrimination	Conditions that report exclusion
Relating to marriage	
Marital – getting married	H, T, S?, E, L, D, MH, B, CD
Marital – dating	H, T, S?, E, L, D, MH, B, CD
Marital – divorce	H, T, S?, E, L, D, MH, B, CD
Marital – conflict	H, T, S?, E, L, D, MH, B, CD
Relating to family	
Family – isolation	H, T, S, E?, L, D, MH, B, CD?
Family – abandonment	H, T, S?, E?, L, D, MH, B, CD
Family – abuse	H, T, S?, E, L, D, MH, B, CD
Family – avoidance	H, T, S, E, L, D, MH, B, CD
Family – or community – over protection	
Relating to friends	
Friends – avoidance, isolation	H, T, S, E, L, D, MH, B, CD
Note: Family, friends, etc. are culturally defined.	

Leprosy (L), SARS(S), Buruli Ulcer(B), TB(T), HIV(H), Epilepsy(E), Mental Health(MH), Cognitive Disability (D), Physical disability (D)

Indicators for policy, political and legal discrimination	Conditions that report exclusion
Structural/physical access issues	
Indicators for community-level discrimination	
Denied livelihood – e.g. as a food seller	H, T, S, E, L, D, MH, B?
Refused membership of clubs, associations	H, T, E, L, D, MH, CD?
Refused membership of religious organisation/community	E, L, D, MH
Disqualified from leadership of religious group	H, T ?, E, L, D, B, MH
Not permitted to participate in church functions	H, T, E, L, D, MH
Not permitted to be a community leader	H, E, L, D, MH, B
Barred from normal social interactions	H, T, S, E, L, D, MH, CD
Withdrawal of normal social support	H, T, S, E, L, D, MH, CD
(Helping others)	
Exclusion from social gatherings and events	H, T, S, E, L, D, MH, CD
Exclusion from public places (e.g. restaurants, transport)	H, T, S, E, L, D?, MH, CD
Exclusion from community resources (e.g. wells, burial grounds)	H, T, S, E, L, D?, MH, CD?

Leprosy (L), SARS(S), Buruli Ulcer(B), TB(T), HIV(H), Epilepsy(E), Mental Health(MH), Cognitive Disability (CD), Physical disability (D)

Appendix 2 Guiding principles: Methodology



Appendix 3 Sample Interventions

Level of Intervention	Intervention
Intrapersonal/ Individual	<ol style="list-style-type: none"> 1. Individual education, empowerment, and skills-building: <ol style="list-style-type: none"> a. Education and empowerment <ul style="list-style-type: none"> ▪ Positive living with the disease (HIV)/positive image building (DIS) (HIV) ▪ Psycho-education (MH) ▪ Awareness of individual rights (HIV) ▪ Building self-esteem (All) ▪ Role reversal/image reversal (DIS) ▪ Understanding and accepting of the illness (L) (TB) ▪ Non-formal education (L) ▪ Education in schools (MH) (DIS) b. Skills <ul style="list-style-type: none"> ▪ Assertiveness, negotiating skills (L) (HIV) ▪ Advocacy skills (L) (HIV) ▪ Problem-solving skills (L) ▪ Coping skills (L) (HIV) ▪ Stress management skills (HIV) ▪ Vocational skills and follow-up (DIS) (L) (MH)/income generating skills (HIV) (TB)/loans (DIS) ▪ Conflict management skills (HIV) ▪ Tailored social skills (based on stage/understanding of illness) (L) ▪ Self-care training (L) 2. Individual counselling: <ul style="list-style-type: none"> ▪ Individual peer counselling (TB) ▪ Individual counselling by health provider (TB) 3. Access to testing, medical care, interventions, treatment, home-based care, psychosocial support, and support for basic health needs
Interpersonal	<ul style="list-style-type: none"> ▪ Activities for the family of affected persons that build upon family strengths (HIV) (BU) ▪ Solidarity groups, support groups, user/client councils (MH) (HIV) (TB) ▪ Family counselling (MH) (TB) ▪ Contact strategies/activities (MH) ▪ Provider/client meetings (TB)

Level of Intervention	Intervention
Organization/ Institutional	<ol style="list-style-type: none"> 1. Awareness building and support structures within health care facilities: <ol style="list-style-type: none"> a. Health care providers <ul style="list-style-type: none"> ▪ Protection ▪ Support ▪ Education, value appraisal ▪ Sensitization activities b. Health care systems <ul style="list-style-type: none"> ▪ Policies ▪ Resources ▪ Structures ▪ Care services ▪ Support structures and services for disclosure 2. Supportive work environment programs
Community	<ol style="list-style-type: none"> 1. Condition/disease image transformation and awareness building through sensitisation activities (focusing on the use of testimonies and the promotion of positive role models and awareness of individual human rights): <ul style="list-style-type: none"> ▪ Media ▪ Drama ▪ Films ▪ Photo exhibitions 2. Community structures and systems that support disclosure 3. Participatory approaches with community members to help identify problems 4. Community-level advocacy through community-based NGOs and the involvement of community leaders (BU) (HIV) (ALL) 5. Community-based rehabilitation (DIS) (L)
Policy/Societal	<ol style="list-style-type: none"> 1. Promotion of human rights: <ul style="list-style-type: none"> ▪ Advocacy ▪ Legal ▪ Awareness ▪ Addressing poverty 2. Non-discriminative legislation (e.g. supportive work environment policies) 3. Societal-level advocacy/protest 4. Societal-level awareness building events/building positive images (i.e. AIDS quilt)
Global	International solidarity movements

Appendix 4 Stigma Consortium

The consortium

This document concerns the terms of reference and structure of the International Consortium for Research and Action Against health-related Stigma (ICRAAS). The consortium will be a partnership of recognized research institutes, organisations and projects with a base in Europe, but with partners from around the world. The focus of the work to be undertaken under the umbrella of the consortium will be in low and middle-income countries.

The scope of the work on health-related stigma is potentially very large and its success will depend on partnerships with high-quality investigators and implementers, particularly in low and middle-income countries. Obtaining funding for this work, particularly for future research projects will require substantial scientific credibility. For these reasons we see great benefit in creating a platform for research and action together with a key investigators and partner institutions and projects that have an established track record in this field.

Aim

To reduce health-related stigma and its harmful consequences, including discrimination and social exclusion.

Strategy

To share, combine and exchange knowledge, expertise, instruments, networks, etc. for future research and action on health-related stigma and discrimination.

Objectives

The main objectives of forming a consortium are

- 1) To facilitate the exchange of knowledge and expertise on health-related stigma and its consequences between researchers working in different public health fields.
- 2) To stimulate action against health-related stigma and action to promote social inclusion.
- 3) To exchange instruments and toolkits between public health fields.
- 4) To support scientists from the South in studying health-related stigma and its consequences and stigma reduction activities.
- 5) To provide a platform for discussion of issues concerning health-related stigma and discrimination.
- 6) To create a multi-discipline forum of scientific excellence in the field of health-related stigma research to guide and monitor research projects carried out under its umbrella.
- 7) To increase scientific credibility of funding applications to major donor agencies made under the umbrella of the consortium.

The consortium will in no way interfere with or try to get involved in any current or future (research) projects of member institutes or organisations without a written request from the concerned member. The consortium will only become involved where such involvement is of benefit to the concerned consortium member. Administrative and managerial responsibility of all projects supported by or carried out under the umbrella of the consortium will be assigned to one of the member institutes or organisations.

Structure

We envisage several partly overlapping 'circles' of collaboration and networking. The 'core group' would comprise a number of institutes, projects and organisations, including those representing people affected by stigma, developing and guiding the consortium (the Steering Committee – see below). Each of these would have or establish a 'circle' of partnerships with other institutes and organisations to carry out research and action on health-related stigma and discrimination. Around these would be a wider network of contacts and collaborations with investigators working on stigma and discrimination and also with people involved in stigma reduction work. People affected by health-related stigma should be involved in each of these circles.

A Consortium Steering Committee (CSC) will be set up comprising the Consortium Coordinator, representatives from consortium partners and independent experts. The CSC will be responsible for key decisions in the areas of:

- Determining the structure, modus operandi and policies of the consortium
- Monitoring of the ICRAAS activities
- Approval of research proposals and protocols to be carried out under the consortium
- Funding applications
- Reviewing the progress and process of projects to be carried out under the consortium
- Reviewing research results
- Reviewing lessons learned from the collaboration
- Planning of consortium meetings

The Chairperson of the CSC will be elected by the committee. The ICRAAS Coordinator will be the Executive Secretary; the CSC will be serviced by the Consortium Secretariat Office. A CSC meeting will be held every six months.

Of people taking part in the consortium we would ask a commitment depending on their level of partnership. Core group members would need to be able to commit enough time to attend twice-yearly CSC meetings, as well as be involved in some of the ongoing activities of the consortium. It is estimated that this would take about one week per year. Core group members would allow their own name or the name of their institute, project or organisation to be listed as a supporting partner in future consortium-approved funding applications. Such applications would of course not be made without their full foreknowledge.

Consortium secretariat

A Consortium Secretariat Office will be set up in Netherlands. The office will be responsible for:

- Liaison with consortium partners
- Representing the consortium in relations with funding agencies regarding project applications submitted under the umbrella of the consortium.
- Preparation of regular reports and financial statements to KIT, consortium partners and funding agencies as required. Progress reports will be sent every six months.
- Developing good and effective communication between partners through the development of a consortium website and regular newsletters to partners.

Membership

Three categories of membership are suggested: supporters, participants and sponsors.

- Supporters are members who support the cause of the ICRAAS, may wish to remain up-to-date with developments and may want to use some of the consortium resources.
- Participants are active members who make use of the resources available through the consortium and who actively contribute to it by sharing their own expertise, tools, etc.
- Sponsors are members who support the ICRAAS financially, either directly by contributing the its running costs or indirectly by making staff time and/or other resources available to the consortium.

Potential members may apply for membership by sending an email application to the Consortium Coordinator, Dr. Wim van Brakel at <StigmaProject@kit.nl>, stating their field of interest, the reason why they would like to join the consortium and the type of membership they would like to have. Criteria for membership will be drawn up by the Steering Committee.

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