

# Stigma and Ebola: an anthropological approach to understanding and addressing stigma operationally in the Ebola response

Ebola Response Anthropology Platform 11/12/2014

Policy Briefing Note

## Key points

1. 'Stigma' is an umbrella term for the direct and indirect consequences of a number of processes that brand someone as different in ways that result in discrimination, loss of status and social exclusion. It can be short-term or evolve into a long-term and life-long issue.
2. Who and how people are being socially labelled – plus the material, political, social and moral consequences of this labelling – often change rapidly throughout the course of an epidemic, particularly from the early stages of an emerging outbreak to an established epidemic.
3. The first step to addressing or seeking to avoid exacerbating stigma is to identify the nature of, and factors influencing, relationships between those associated with Ebola and the rest of society. Every policy decision should be made with consideration for its immediate and long term consequences for each social group affected.
4. Efforts to de-stigmatise Ebola should focus on improving the social visibility and the physical, economic and social wellbeing both of groups affected by stigma and, importantly, of their neighbours and wider social networks.

## Unpicking Ebola-related Stigma

5. Understanding stigma requires a broader understanding of how those with, recovering from or associated with Ebola Virus Disease (EVD), are related to by others, in particular how they are:
  - a. Shunned or not
  - b. Cared for and supported or not
  - c. Ill-treated or not
  - d. Economically and politically excluded or not
6. People who may be particularly susceptible to Ebola-related stigma include:
  - a. Those unwell with symptoms compatible with Ebola, whether or not in formal care
  - b. Those who have survived EVD
  - c. The family/households of either of the above, particularly those under active isolation/quarantine
  - d. Those working or otherwise regularly in contact with any of the above
  - e. Those who are already marginalised or discriminated against
  - f. Those involved in early vaccine or intervention distribution, in particular through trials
7. Stigma is enacted around particular spaces and objects. Any analysis of stigma therefore needs to understand which spaces and objects stigma is 'done' through.

## Stigmatising processes in the context of Ebola

8. Many stigmatising processes develop from a fear of the unknown. Stigmatising processes are therefore likely to be different at the beginning of an outbreak, particularly of a disease that is previously unknown in the area, than once the outbreak is established.
9. Once an epidemic is established and becomes less of an 'unknown', stigmatising labels and processes that develop early in the response may nevertheless become routinised and socially embedded. An example of this is the HIV epidemic, where stigma has reduced significantly particularly where effective treatment is available, yet there has been a normalisation of what stigma of the afflicted persists.
10. It is important to note that processes which stigmatise infectious individuals may have positive consequences for transmission rates. Any process that introduces physical distance between the infectious and the susceptible will reduce transmission, plausibly playing a role in local responses to infectious epidemics.
11. However, physical separation does not necessarily entail negative labelling or consequences. Local cultural protocols for managing epidemic illnesses have been described in Ebola-endemic regions areas which emphasise physical distance from the afflicted without recourse to moralised labels.
12. Organisations and institutions themselves often intentionally or unintentionally contribute to stigmatising processes through 'institutional bias' or attribution of medical, beneficiary or militaristic labels. An organisation wishing to address stigma should therefore first consider ways in which their own policies favour or discredit certain practices or groups, then consider the impact of other formal and informal institutions that are active in their target population.
13. Those making and implementing policy seeking to address or avoid exacerbating stigma should be sensitive to how events and interventions:
  - a. Ascribe positive or negative labels to certain people or groups and what the long-term consequences of those labels could be
  - b. Are socially isolating or divisive
  - c. Contribute to uncertainty or the 'unknown' by concealing people or events
  - d. Differentially affect the physical, economic, political, religious or social wellbeing of different people or groups
14. While many of the factors affecting these processes are context- and group-specific, cross-cutting factors that contribute to many stigmatising processes include:
  - a. Different aetiological understandings of Ebola – in particular those that moralistically ascribe the outbreak to moral or other wrongdoing on the part of the individuals, communities or countries affected.
  - b. The interpretation and flow of information between diaspora communities and those they have maintained connections with in their home countries.
  - c. The interaction between Ebola-specific social processes and existing social divisions, prejudice and making and unmaking of negative labelling.
  - d. The political context of the Ebola response. No matter what policy decision is made, it will be interpreted as political, therefore attention should be paid to the symbolic importance of any site, intervention or beneficiary group.

- e. Militarisation of the Ebola response and healthcare delivery, with particular regard to national and international military actions during the civil war and the long term consequences of this.
- f. Labelling of particular organisations, and the goods and services they provide, on the basis of their perceived positive or negative contributions to the Ebola response.

### De-stigmatising Ebola

15. The two most effective interventions to de-stigmatise an illness are a) to improve survival and knowledge of the ability to survive, and b) to prevent catastrophic economic consequences of those actually or potentially suffering from the illness.

16. In the absence of curative treatment, addressing Ebola-related stigma requires a reduction in the social isolation, marginalisation and the negative connotations of those associated with Ebola

17. It is important to be culturally sensitive, dynamic in responses and plan sustainably with local partners for long-term engagement. It may be useful to think of how to support the wider group first, then those individuals within the group who are subject to stigmatising processes in order to demonstrate a benefit to both.

18. Efforts to de-stigmatise Ebola should therefore aim to improve the physical, economic or social wellbeing and social visibility of those groups associated with Ebola, as well as the wellbeing of their broader social networks.

19. For example, giving households under quarantine a 'compensation' or 'solidarity' kit that ensured access to a charged phone, phone credit and a mobile phone cash transfer to cover the cost of food for the duration of the quarantine would not only mitigate some of the socially isolating effects and negative household economic consequences of quarantine, but potentially transform the perception of quarantined households into potential economic opportunities for their neighbours.

20. It is important that these households are not stigmatised again by receiving these kits and that they are intrinsically linked to ensuring the well-being of the community as a whole. It would be appropriate to extend compensation to the wider community as an acknowledgement and thanks for non-formal support that has been extended to the household under quarantine.

21. Lessons can be drawn from ex-combatant reintegration programmes after the civil war in Sierra Leone. For example, punch-cards given to ex-combatants that showed their engagement with reintegration programmes became a highly valued symbol of their reintegration into society and of their break with their previous military life. A similar system could be implemented for example with household under quarantine to recognise adherence with transmission control procedures and symbolise the end of the 'risk' they pose to other.

Annex: Suggested matrix for assessing and reducing the stigmatising effects of a policy decision

Policy Consideration	Stakeholder groups <i>Requires initial then repeated fieldwork to identify locally important subgroups under each heading</i>			
	People directly targeted by policy (including gender analysis)	Existing marginalised/ stigmatised groups	Field staff delivering the policy	Other social groups not directly targeted
1. What <b>social differences/divisions</b> are generated or reconciled by the policy?				
2. What <b>physical, economic, political, religious or social benefits</b> does the policy entail for each group?				
3. What undesirable <b>physical, economic, political, religious or social harms</b> does the policy entail for each group?				
<b><i>Interim summary: likely stigmatising/de-stigmatising effects of current policy</i></b>				
4. How can the above <b>harms be mitigated</b> in a way that is consistent with the policy's primary aims?				
5. How can social, economic or political <b>cohesion between each group be strengthened</b> in a way that is consistent with the policy's primary aims?				
<b><i>Final summary: likely stigmatising/de-stigmatising effects of revised policy</i></b>				

## Authorship and Contributors

*We gratefully acknowledge the following people, in alphabetical order, who contributed to the advice given in this briefing note:*

Maria Berghs (University of York)  
Clare Chandler (LSHTM)  
James Fairhead (University of Sussex)  
Mariane Ferme (university of California, Berkeley)  
Amber Huff (Institute of Development Studies, Sussex)  
Ann Kelly (University of Exeter)  
Melissa Leach (Institute of Development Studies, Sussex)  
Fred Martineau (LSHTM)  
Esther Mokuwe (Njala University, Sierra Leone)  
Pauline Oosterhoff (Institute of Development Studies, Sussex)  
Melissa Parker (LSHTM)  
Paul Richards (Njala University, Sierra Leone)  
David Rubyan-Ling (University of Sussex)  
Annie Wilkinson (Institute of Development Studies, Sussex)

*This briefing notes represents the views of the Ebola Response Anthropology Platform, funded by the Research for Health in Humanitarian Crises (R2HC) Programme, managed by Enhancing Learning and Research for Humanitarian Assistance (ELRHA).*

*The R2HC programme aims to improve health outcomes by strengthening the evidence base for public health interventions in humanitarian crises. Visit [www.elrha.org/work/r2hc](http://www.elrha.org/work/r2hc) for more information. The £8 million R2HC programme is funded equally by the Wellcome Trust and DFID, with ELRHA overseeing the programme's execution and management.*