Assessing and reducing stigma in infectious disease outbreaks

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To all I have called home,
who have still taught me the most valuable things I know.

Abstract

Stigma is a pervasive challenge in infectious disease outbreaks. It repeatedly hinders outbreak response efforts, deepens socioeconomic divides, and causes lasting harm to affected individuals and communities. Despite this, efforts to monitor and address stigma during outbreaks have often been ad hoc, delayed, or poorly integrated into response planning. This thesis sets out to advance the assessment and reduction of stigma in outbreak contexts by developing tools and recommendations for response teams, including those conducting operational research.

The thesis contains four chapters of original research. Chapter 2 presents a systematic review of the content and psychometric properties of stigma scales used in outbreaks. Chapter 3 reports findings from qualitative interviews with international stakeholders examining how stigma is understood, experienced, and addressed in diverse settings. Chapter 4 includes a cross-sectional community survey conducted in three outbreak contexts (mpox in the UK, Ebola disease in Uganda, and Nipah virus disease in Bangladesh), with these data used to validate new stigma assessment tools. Chapter 5 brings together an evidence review and a structured expert consensus process to develop practical stigma mitigation guidelines for public health actors and response organisations.

The findings demonstrate the value of more structured, evidence-informed responses to stigma. Existing stigma assessment tools were found to lack validity, largely due to scale development and validation processes that are poorly suited to acute outbreaks. A new conceptual model of outbreak-related stigma was developed based on stakeholder interviews spanning 25 outbreak-prone infectious diseases, offering practical insights for considering stigma in response planning. Survey data from over 1000 respondents supported the development of a set of stigma scales that performed well across the three diverse outbreak contexts. Building on these empirical foundations, an international expert panel reached consensus on nine guiding principles and 18 actionable recommendations to support more effective, stigma-sensitive public health responses.

Together, the outputs of this research offer a basis for integrating stigma considerations into outbreak preparedness and response. In doing so, they support efforts to improve the recovery, reintegration, and wellbeing of affected individuals and communities. Future research is needed to explore longitudinal monitoring and evaluate promising stigma reduction strategies now that these are more clearly defined.

Acknowledgements

Over the last few years, the work captured in these pages has often felt ambitious. Now that it is done, it seems the smallest drop in the ocean of what needs doing. But that it is done at all is to the credit of many.

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There is a saying from home *Umuntu ngumuntu ngabantu* (a person is a person through people) that has sat with me throughout this work. I thank those who taught me its meaning, who are the reason any of this has been set and kept in motion.

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Declaration

I declare that this thesis is my original research and has not been submitted for a degree at any other university. It includes material from the following peer-reviewed publications, which I first-authored or co-authored as a doctoral student:

- **Paterson A**, Olliaro PL, Rojek A. Addressing stigma in infectious disease outbreaks: a crucial step in pandemic preparedness. *Frontiers in Public Health.* 2023.
- **Paterson A**, Cheyne A, Jones B, Schilling S, Sigfrid L, Stolow J, et al. Systematic review of scales for measuring infectious disease–related stigma. *Emerging Infectious Diseases.* 2024.
- **Paterson A**, Jones B, Kabajaasi O, Cheyne A, Tulunay H, Hadson K, et al. An hourglass model for conceptualising stigma in infectious disease outbreaks. *Scientific Reports.* 2025.
- **Paterson A***, Kabajaasi O*, Adlard F, Hadson K, Cheyne A, Ssewankambo Y, et al. Ebola stigma and its impact on outbreak control: lessons from key informant interviews in central Uganda. *Tropical Medicine & International Health.* 2025. (*joint first authorship)
- **Paterson A**, Mughogho KM, Cheyne A, Kabajaasi O, Sarkar T, Dimitrios KH, et al. The (Re)-emerging And ePidemic Infectious Diseases (RAPID) Stigma Scales: a cross-outbreak scale development and psychometric validation study. *The Lancet Infectious Diseases.* 2025.
- **Paterson A**, Cheyne A, Tulunay H, Orkin C, Nutland W, Dunning J, et al. Mpox stigma in the UK and implications for future outbreak control: a cross-sectional mixed methods study. *BMC Medicine.* 2025.
- Rojek A, Fieggen J, **Paterson A***, Byakika-Kibwika P, Camara M, Comer K, et al. The Modern Landscape of Ebola series: Embedding treatment in stronger care systems. *The Lancet Infectious Diseases.* 2025. (*stigma section author)

Where the thesis includes the work of others this has been credited within the respective chapters.

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List of Abbreviations

CASP	Critical Appraisal Skills Programme
CDC	Centers for Disease Control and Prevention
CERQual	Confidence in the Evidence from Reviews of Qualitative research
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
CI	Confidence Interval
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
CVI	Content validity index
COVID-19	Coronavirus Disease 2019
DRC	Democratic Republic of the Congo
EFA	Exploratory Factor Analysis
EVD	Ebola Virus Disease
GBMSM	Gay, Bisexual, and other Men who have Sex with Men
GOARN	Global Outbreak Alert and Response Network
GRADE	Grading of Recommendations Assessment, Development, and Evaluation
HIV	Human Immunodeficiency Virus
ICCPR	International Covenant on Civil and Political Rights
IFRC	International Federation of Red Cross and Red Crescent Societies
IQR	Interquartile Range
ISARIC	International Severe Acute Respiratory and Emerging Infection Consortium
KMO	Kaiser-Meyer-Olkin measure of sampling adequacy
N/A	Not Applicable
N/S	Not Specified
OR	Odds Ratio
PHEIC	Public Health Emergency of International Concern
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PROSPERO	International Prospective Register of Systematic Reviews
PSI	Pandemic Sciences Institute
RAPID Scales	(Re)-emerging And ePidemic Infectious Diseases Scales
RCT	Randomised Controlled Trial
REDCap	Research Electronic Data Capture
RMSEA	Root Mean Square Error of Approximation
ROBINS-I V2	Risk Of Bias In Non-randomized Studies of Intervention Version 2
RoB 2	Revised Cochrane risk of bias tool for randomised trials
SARS	Severe Acute Respiratory Syndrome
SRMR	Standardised Root Mean square Residual
Stigma-SCANR	Stigma Survey and Community-based Assessment for New and Re-emerging outbreaks
UDHR	Universal Declaration of Human Rights
UK	United Kingdom
US	United States of America
WHO	World Health Organization

Glossary of Key Terms

Term	**Definition**
Affected community	A group of people with shared context who have direct or indirect experience of an outbreak.
Community engagement	The process of working with communities to address health-related issues, promote wellbeing, and support changes in behaviour, environments, or policies.
Experts	Individuals invited to provide input on tools based on academic, operational, or lived experience, as identified through publications, organisational role, or recognition within community networks.
Infectious disease outbreak	A sudden and unexpected rise in cases of a pathogen caused by a pathogen in a defined community, geographical area, or time period. Within this thesis, this term encompasses outbreaks of varying scale, including epidemics and pandemics.
Outbreak response organisation	Organisations that prevent, investigate and/or manage outbreaks. This includes public health agencies, ministries of health, civil society organisations, healthcare services, and research institutions.
People with lived experience	Individuals who have or previously had the outbreak-related infectious disease of concern. This does not require having received medical care.
Psychosocial support	Actions that address the psychological and social needs of individuals, families, and communities to promote wellbeing and social cohesion.
(Re)emerging infectious diseases	Diseases caused by infections that have newly appeared or reappeared in a population, or that are rapidly increasing in incidence or geographic range.
Risk communication	The exchange of information, advice, and opinions between officials and the public during a threat to enable informed decisions and protective actions.

Term	Definition
Social listening	The process of collecting and analysing information from media and community platforms to understand public beliefs, attitudes, and intentions regarding health risks and related policies.
Stakeholders	Actors who have an interest in the issue under consideration, who are affected by decisions about it, or who can influence relevant decision-making processes.
Stigma	The result of a social process whereby a person or group is denied full acceptance and inclusion due to an attribute deemed discrediting in their society. This umbrella term includes negative beliefs and attitudes (i.e. prejudice) and behaviours, including differential treatment resulting in disadvantage, harm, or exclusion (i.e. discrimination).

1

Introduction

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1.1 Chapter preface

1.1.1 Overview

Stigma is a recurrent and insidious feature of infectious disease outbreaks. This chapter begins by situating stigma research within the context of outbreak preparedness and response. It then traces the concept of stigma and its association with infectious diseases from antiquity to contemporary events, and provides a rationale for the cross-outbreak approach taken in this thesis. Following this, the aims, objectives, and structure of the thesis are outlined. The remainder of the chapter sets out the parameters of inquiry, including the scope of the research, the epistemological position from which it is approached, and my own positionality.

1.1.2 Publication and contributions

This chapter contains content from the following publications:

- **Paterson A**, Olliaro PL, Rojek A. Addressing stigma in infectious disease outbreaks: a crucial step in pandemic preparedness. *Frontiers in Public Health.* 2023. (Background)
- **Paterson A**, Cheyne A, Jones B, Schilling S, Sigfrid L, Stolow J, et al. Systematic review of scales for measuring infectious disease–related stigma. *Emerging Infectious Diseases.* 2024. (Figure 1.1)
- Rojek A, Fieggen J, **Paterson A**, Byakika-Kibwika P, Camara M, Comer K, et al. The Modern Landscape of Ebola series: Embedding treatment in stronger care systems. *The Lancet Infectious Diseases.* 2025. (Figure 1.2)

I wrote the first drafts of all included material and created all figures.

1.2 Background

1.2.1 Situating stigma research in outbreak preparedness

In a 2020 public address on COVID-19, the Director-General of the World Health Organization (WHO) warned that stigma may be “more dangerous than the virus itself”.[1] This concern has since gained policy traction. The importance of preventing stigma is now explicitly recognised in the WHO Pandemic Agreement, adopted by member states in May 2025.[2] In addition, the same Assembly adopted a resolution to strengthen the evidence base for public health and social measures.[3] This resolution calls for robust studies assessing the adverse effects of outbreak response measures across settings. It also emphasises the need for the integration of socio-behavioural models into outbreak research.[3] A further resolution focuses on fostering social connection, calling for countries to strengthen social monitoring systems and address the drivers of social disconnection.[4] Together, these developments reflect growing recognition that mitigating social harms, including stigma, is integral to effective outbreak response and community wellbeing.

Despite growing recognition of the harms of stigma, guidance on how to monitor and mitigate outbreak-related stigma remains limited. Response teams lack tools for tracking stigma in real time and decision-making frameworks that incorporate the risk of stigma. There is also a lack of evidence-based guidance or expert consensus on which stigma reduction interventions are likely to be successful in outbreaks. These gaps can make it difficult to recognise when outbreak control efforts may be exacerbating stigma, or to respond quickly when divisive social dynamics emerge. As a result, stigma is often addressed reactively in an ad hoc, superficial manner rather than as a deliberate and integrated component of outbreak response. Generating robust evidence, tools, and guidance for stigma mitigation therefore represents an opportunity to improve outbreak preparedness and response.

The relevance of this work is underscored by the increasing frequency and scale of (re)emerging infectious disease outbreaks.[5] Over the past two decades, the WHO has declared eight Public Health Emergencies of International Concern (PHEICs), including for H1N1 influenza, polio, Zika virus disease, COVID-19, and two each for Ebola disease and mpox.[6,7] Modelling studies suggest that pandemic risk may increase up to threefold in the coming decades, driven by global mobility and environmental change.[8,9] In addition, smaller-scale outbreaks are common: infectious diseases have been the leading cause of acute public health events in the past five years, accounting for approximately 80% of reported events in a given year.[10] In this context, there is a need to ensure that all aspects of outbreak response are critically evaluated and optimised. This imperative is both moral, in terms of preventing social harm, and practical, in addressing behavioural drivers of disease transmission.

1.2.2 Conceptual overview of stigma

The term stigma originates from the ancient Greek verb στίζω, which means 'to mark as a sign of shame, punishment, or disgrace'.[11]

In ancient Graeco-Roman society, this term was used to describe the markings tattooed onto slaves and lawbreakers to warn the public of their social status or deviant behaviour.[12] The visible branding and clipped ears of criminals in medieval Europe were similarly referred to as stigmata.[13] By the 18th century the term stigmata was extended to refer to physical evidence of disease on medical examination[14]; a meaning which remains in use today.

It was in the 20th century that scholars first described stigma as a social construct rather than a fixed physical trait.[14] A pivotal figure in this development was sociologist Erving Goffman. In his 1963 text, *Stigma: Notes on the Management of Spoiled Identity*, Goffman argued that in defining stigma "a language of relationships, not attributes, is really needed".[15]

It is this *relational* definition that has continued into modern use. That is, today stigma refers to the result of a social process whereby a person or group is discredited and marginalised due to an attribute deemed undesirable by their society, rather than referring to the attribute itself.[14,15] This distinction is important as it recognises that the issue of stigma does not reside within the stigmatised individual, but rather within the broader social context in which they live.[14]

As the stigma literature has grown, multiple conceptual frameworks have been proposed. These use varying terminology and frameworks which can, at times, be confusing and contradictory. For example, the term 'felt stigma' has been used as a synonym for perceived stigma,[16] self stigma,[17] anticipated stigma,[18] and a combination of these terms.[19]

There is, however, relative consensus on the basic conceptualisation of stigma as a continuum of stereotypes, prejudice, and discrimination (Figure 1.1).[20–22] In this continuum, stereotypes provide the cognitive foundation for stigma, but awareness of a stereotype alone does not constitute stigma.[20] Rather, stigma arises when these stereotypes are endorsed (i.e. prejudice) and acted upon in ways that disadvantage others (i.e. discrimination) (further considerations in Box 1.1).[20]

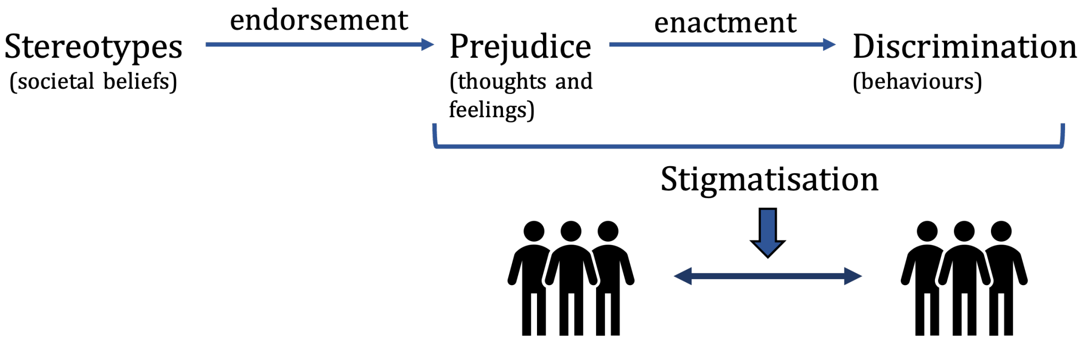


Figure 1.1: Conceptualisation of stigma; based on Corrigan and Watson[20] and Goffman[15]; adaptation of figure published in Paterson et al.[23]

Box 1.1: Terminology considerations

In advocacy-oriented documents, the phrase 'stigma and discrimination' is often used. The addition of 'discrimination' is thought to convey the gravity of the issue more strongly.[24,25] However, to maintain conceptual consistency, stigma is used as an umbrella term throughout this thesis.

It is widely recognised that stigma is not merely a matter of ignorance, but inherently tied to power and social control.[25,26] Link and Phelan[26] argue that there are three primary purposes for stigma, all rooted in power: to exploit (keep people down), to enforce conformity (keep people in), and to avoid (keep people away).

In the context of disease-related stigma, an important qualification is that acts of avoidance are only considered stigmatising when they are medically unwarranted.[27] Avoiding physical contact with someone with active Ebola disease is, by this definition, not considered stigmatising. However, avoiding contact with someone because they previously had Ebola disease, despite no ongoing infection risk, would be.

Finally, disease-related stigma is not restricted to those who are diagnosed with the illness. It frequently extends to associated individuals, such as those in close proximity or who share aspects of social identity. For example, people of Asian descent were stigmatised during both the 2003 Severe Acute Respiratory Syndrome (SARS) epidemic and the COVID-19 pandemic due to perceived associations with their emergence.[28,29]

1.2.3 Drivers of stigma in infectious disease outbreaks

Infectious diseases have long been accompanied by stigma. This association spans from early religious links between sinfulness and leprosy (also called Hansen's disease),[30] to recent online hostility towards gay, bisexual, and other men who have sex with men (GBMSM) linked to the global outbreak of mpox (formerly monkeypox).[31] The renaming of both conditions was driven by an imperative to separate them from this accompanying stigma.[32,33]

Infectious disease outbreaks are susceptible to stigma for a variety of reasons. Some of these reasons are related to the pathogens themselves. Pathogen characteristics such as unfamiliarity, high transmissibility, visible or severe symptoms, and limited treatment options can evoke fear, uncertainty, and embarrassment.[34,35] Such reactions impact social responses to those affected.[34,35]

Contextual factors also shape the emergence of stigma. The early phase of an outbreak is typically limited to specific geographic or demographic groups, which can predispose to stereotyping.[36–38] There is also often a disproportionate impact on populations who already experience other forms of stigma. This facilitates “moral-piggybacking”,[39] a concept explored in Chapter 3. Media framing plays an important role in this process, often amplifying fear and vilification of marginalised groups.[29] As an outbreak spreads, each social context it enters has pre-existing sociocultural beliefs about illness and established norms for responding to those who fall ill. These can either further precipitate or protect against stigma.

Although often overlooked, stigma can also be driven by the actions taken to control an outbreak. This is particularly the case when control efforts involve intrusions on privacy or abatement of individual freedoms. Table 1.1 provides illustrative examples of how outbreak control measures have contributed to stigma.

Table 1.1: Examples of outbreak response activities contributing to stigma

Outbreak response activity	**Illustrative example of stigma risks**
	Surveillance, testing, and analytics
Contact tracing	COVID-19 contact tracing in Vietnam contributed to individual assignment of blame for subsequent illness.[40]
Surveillance in communities	Surveillance of hantavirus-affected communities in the US was believed to heighten stigma due to invasive home visits creating a sense of criminality.[41]

Continued on next page

Table 1.1 – continued from previous page

Outbreak response activity	**Illustrative example of stigma risks**
Test result notification	A practice of placing notices on COVID-19-affected homes in India had to be discontinued after growing concerns that the resulting public stigma was discouraging testing.[42]
Case management and infection prevention and control	
Use of protective equipment	Use of hazmat suits and other protective equipment in Ebola disease and COVID-19 care settings was reported to amplify feelings of otherness for patients and healthcare workers.[43–45]
Quarantine	A review of the psychological impacts of quarantine across outbreaks identified enduring stigma as a common theme.[46]
Safe burial protocols	The prohibition of customary burial rites during Ebola disease and Nipah virus disease outbreaks has been perceived as disrespectful and stigmatising in some communities.[47,48]
Risk communication and community engagement	
Fear-based risk communication	Warnings against the use of fear appeals (i.e. scare tactics) during COVID-19 highlighted that these messages can heighten moral judgement and distrust in public health authorities.[49]
Messaging emphasising link between disease and hygiene	In Mexico, dengue prevention messaging that emphasised household cleanliness contributed to perceptions that those infected were unclean or negligent.[50]
Messaging associating disease with specific populations	References to COVID-19 as the ‘Chinese virus’ or framing mpox as an African disease were recognised as drivers of associative stigma.[37,51,52]

Subheadings are based on outbreak response pillars as defined by the Global Outbreak Alert and Response Network (GOARN) Steering Committee.[53]
COVID-19 = Coronavirus Disease 2019; US = United States.

These examples illustrate that even necessary public health interventions can have unintended social consequences, especially when implemented without attention to community perceptions or the risks of blame and exclusion.

Importantly, the risk of worsening stigma does not in itself discredit outbreak response measures. Public health actions frequently require difficult trade-offs and the acceptance of some degree of collateral harm.[29] However, these harms need to be recognised, robustly assessed, and mitigated as far as possible. This requires moving beyond response measures that are based solely on biomedical considerations. Instead, decision-making has to acknowledge complexity, anticipate risks, and prioritise both physical and psychosocial wellbeing.

1.2.4 Impact of stigma on individual and community wellbeing

The social and psychological toll of outbreak-related stigma can be profound.[25] Several studies have found that Ebola- and COVID-19-related stigma are significantly associated with symptoms of depression, anxiety, insomnia, and post-traumatic stress disorder.[54–58] These mental health conditions are often stigmatised themselves, compounding the burden of stigma for those affected.[59] This burden can also be prolonged, with psychological consequences persisting long after the acute phase of an outbreak. For example, in a cross-sectional study of 20 Ebola survivors from the 1995 outbreak in the Democratic Republic of the Congo (DRC), participants continued to report significantly higher levels of depression and anxiety than their close contacts more than two decades later, after adjustment for demographic variables.[60] A similar study conducted after the 2018 outbreak in the DRC found that suicide attempts were six times higher among a sample of 223 Ebola survivors than in a community-based comparison group.[61] While these findings are based on relatively small sample sizes, they are nevertheless concerning.

More broadly, stigma is increasingly recognised as a social determinant of health.[62] It exacerbates socioeconomic inequalities by restricting access to resources and opportunities for marginalised groups and heightening isolation.[29,62] This was observed during the 1993 Hantavirus outbreak in the United States (US), where media use of the term ‘Navajo disease’ led to a decline of tourism in the Native American Navajo Nation reservation, reducing local income.[41] A further example was evident in the SARS outbreak a decade later. At the peak of this outbreak, the US Centers for Disease Control and Prevention (CDC) hotline reported 187 calls in a single month related to concerns about buying Asian merchandise.[29] Frequent calls about working with, living near, or going to school with people of Asian descent were also reported.[29] These responses illustrate how stigma can fuel community fragmentation, often when societal trust and cohesion are most critical.[29,63]

Enduring social consequences of stigma, such as ostracisation, can also contribute to physical illness.[64] Evidence suggests that social isolation is associated with an increased risk of stroke, heart disease, diabetes, and cognitive decline.[64] In this way, stigma may also contribute to the burden of chronic disease.

1.2.5 Public health consequences of stigma

Another immediate reason to address stigma is its ability to impede outbreak control. Although control efforts may foster stigma initially, once established, stigma can in turn compromise all pillars of outbreak response. This could be thought of as a negative feedback loop (Figure 1.2).

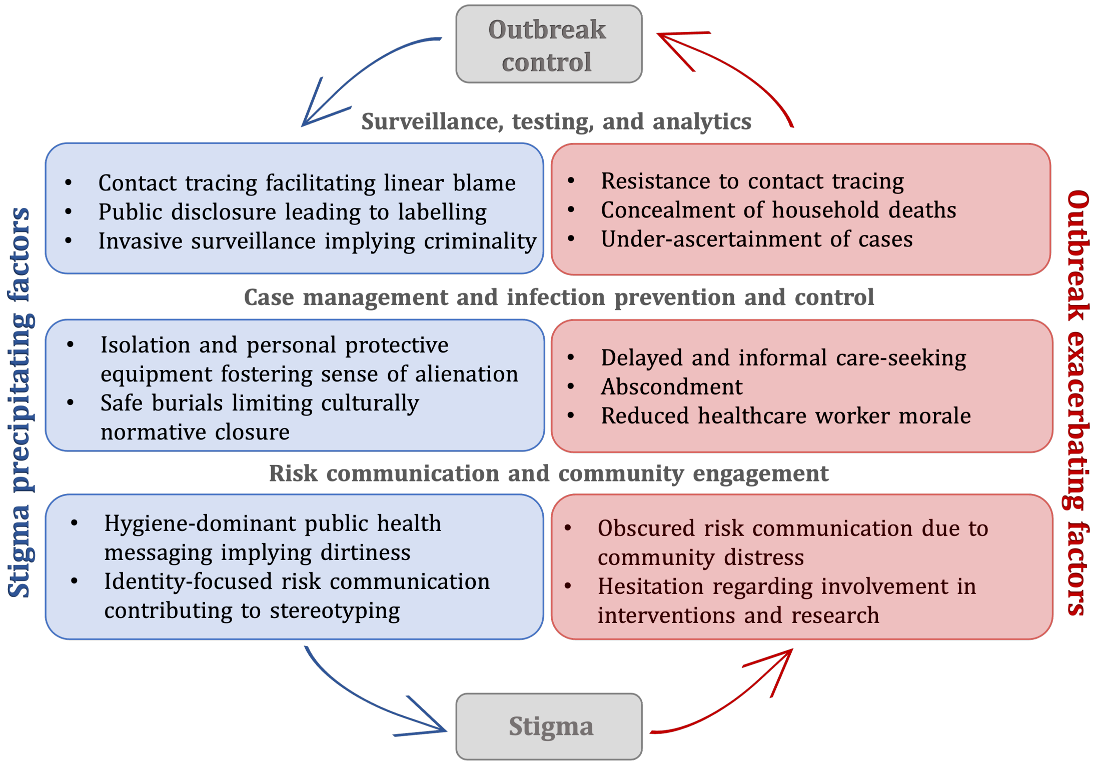


Figure 1.2: The interplay between stigma and infectious disease outbreak control. Subheadings are based on outbreak response pillars as defined by the GOARN Steering Committee[53]; adaptation of figure originally published in Paterson et al.[65] and further adapted for Rojek et al.[66]

The adverse effects of stigma on outbreak response efforts have been repeatedly observed. For instance, during the West African Ebola disease epidemic, contact tracers encountered community hesitancy to disclose information, preventing timely intervention.[67] Testing efforts, both in this epidemic and the COVID-19 pandemic, similarly suffered from denial and concealment of symptoms.[43,68] The resulting avoidance of testing facilities led to continued community transmission and distorted epidemiological analyses.[43,68,69]

Stigma is also frequently cited as a social barrier to disease countermeasures.[29,47,50,70] This complicates disease prevention and management. For example, during the global mpox outbreak, stigma was viewed as a deterrent to vaccine uptake.[31] In addition, stigma can impact outbreak responder safety. A cross-sectional study of over 7,000 participants in 173 countries found that healthcare workers were at an increased risk of COVID-19-related bullying and harassment.[71] In these circumstances, fear and low morale among staff may lead to reluctance to treat those with signs of infection. The 1994 bubonic plague outbreak in Western India provides a striking example of this, where 78% of formal healthcare staff fled the most affected areas within a week of public confirmation of the outbreak.[63] Another example was observed in Hong Kong during the 2003 SARS outbreak, where residents of an affected housing estate reported being refused medical care.[52]

Risk communication and community engagement efforts have been similarly undermined by stigma. For example, in Nigeria stigma-related hesitancy to seek care for Lassa fever symptoms was noted to limit access to accurate information on preventing transmission.[72] In Spain, a qualitative study of pregnant women diagnosed with Zika virus found that many women chose to rely on the internet for information, despite perceiving it as alarmist and unreliable, rather than opting for less anonymous interpersonal sources.[73] Lastly, stigma has been reported to prevent public and patient involvement and hinder recruitment for clinical research, making it more difficult to obtain adequate sample sizes.[74,75]

Intentionally inciting stigma has historically been used as an outbreak control strategy and continues to be proposed.[76] Such approaches have been criticised for their disproportionate impact on those least able to comply with preventive measures.[76] The examples above make a further case for why reliance on stigma as a control tactic is not only unethical, but also counterproductive.

1.2.6 The case for cross-learning in stigma research

Established infectious disease contexts, such as HIV, provide clear examples of how stigma can be addressed through focused policy and programmatic efforts. For example, the United Nations Political Declaration on HIV and AIDS[77] and the Global AIDS Strategy[78] have introduced specific stigma-related targets, referred to as the 10-10-10 goals. These commit countries to reforms that ensure fewer than 10% of people living with HIV and associated populations experience stigma, and fewer than 10% of countries retain laws or policies that impede access to services.[77,78]

As a result of these commitments, HIV stigma is now carefully monitored and addressed as part of coordinated national and global responses.[79] Robust tools have been designed to support these activities. For example, the People Living with HIV stigma index was developed to evaluate the effect of HIV stigma on public health in a standardised manner.[80] It has subsequently been used for public health and advocacy purposes in more than 100 countries with over 100,000 participants.[80]

While new and re-emerging infectious disease outbreaks would benefit from similar attention, they present distinct challenges for tool development: many of these diseases are rare, occur sporadically, and emerge at unexpected times and locations. Although high impact, their duration is often brief. A stigma tool designed reactively to an outbreak is therefore unlikely to facilitate timely intervention and risks compromising validity if developed quickly.[81] In addition, local outbreak responders may not have the capacity to create such a tool in resource-limited settings, or amongst competing demands even in high-resource settings.

Cross-outbreak stigma research offers a pragmatic solution to these challenges. By allowing tool development to begin in advance of the next outbreak, it could enable more timely responses to future outbreak-related stigma.[34,82] This aligns with pandemic preparedness efforts that include solving for "disease X" – a placeholder name that represents an as yet unknown emerging pathogen.[83] Such an approach is particularly relevant given the limitations of pathogen-specific risk forecasting and possibility of future epidemics arising from unrecognised pathogens.[84,85] The scale of this uncertainty is considerable, with an estimated 1.7 million undiscovered viruses thought to exist in the natural environment.[86]

Importantly, developing stigma research tools that can be used across diseases and settings is considered feasible.[34,82,87,88] This is because, although outbreaks differ in many respects, there are notable similarities in the manifestations of stigma and approaches to stigma reduction across contexts.[19,25,35,88–90]

1.3 Research framing

1.3.1 Aim and objectives

The aim of this thesis is to develop and validate a set of tools to assess and reduce stigma in infectious disease outbreaks.

This aim is operationalised through the following objectives:

1. Review existing scales used to assess outbreak-related stigma
2. Develop a conceptual model to facilitate structured consideration of stigma in future outbreaks
3. Design stigma assessment tools that are broadly applicable in a wide range of outbreaks
4. Validate the assessment tools in three outbreak-affected communities
5. Develop guidance for mitigating stigma in future outbreaks

1.3.2 Thesis structure

Figure 1.3 provides an overview of how the original research chapters address each thesis objective.

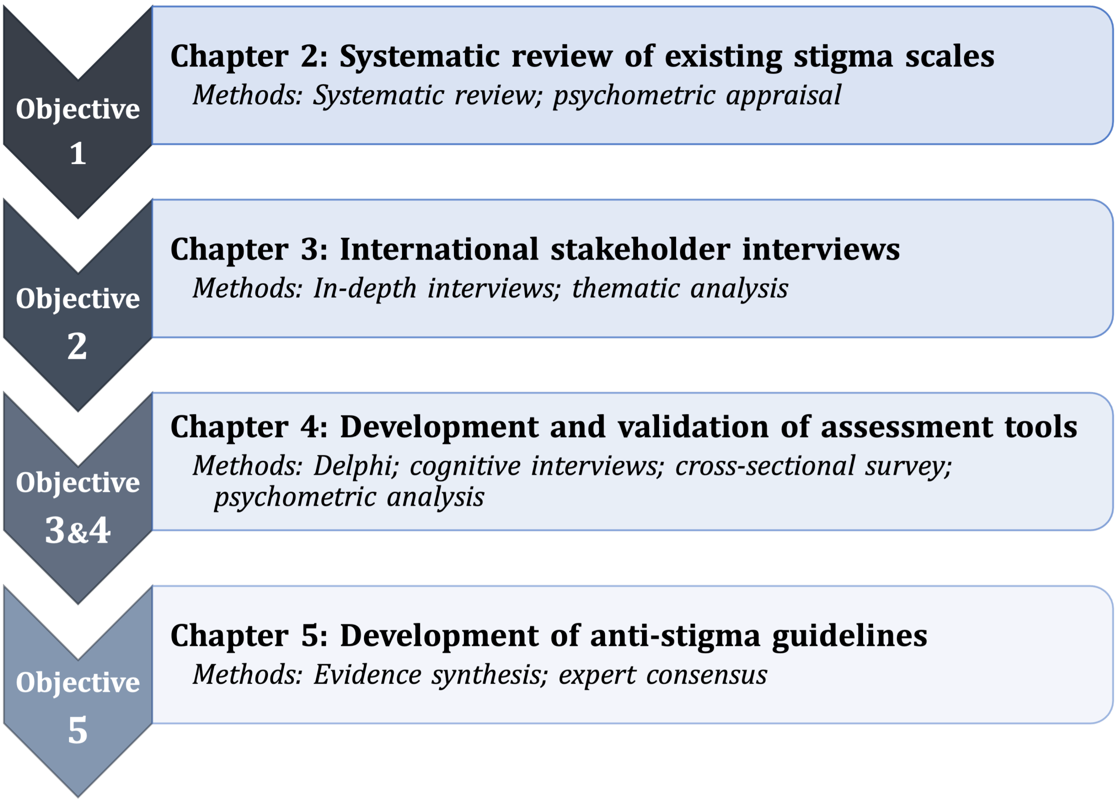


Figure 1.3: Relationship between thesis objectives and chapters

1.4 Parameters of inquiry

1.4.1 Scope

This thesis focuses on outbreak-affected communities. The term ‘community’ is dynamic and can be defined in several ways, including by location, culture, and shared traits or experiences, and at a variety of levels, from local to international.[91] Individuals can therefore belong to multiple communities simultaneously, adding complexity to the concept.[91]

In this thesis, the term community refers to a group of individuals with shared context who have direct or indirect experience of the same infectious disease outbreak. This includes individuals currently or previously diagnosed with the disease, family and friends of these individuals, and members of the public living in a village, town, or city affected by an outbreak, or who otherwise identify with the affected population group.

I have considered healthcare workers as a subcategory of outbreak responders in this thesis, and as a component of the broader outbreak-affected community. While acknowledging healthcare workers' distinct experiences, I have intentionally limited reliance on frameworks and tools that focus exclusively on this group. There are several reasons for this decision. Firstly, early project collaborators cautioned that exceptionalising healthcare workers as distinct from the affected community might reinforce the 'us versus them' divide that underpins stigma. Secondly, throughout this project I have been in contact with another research team working on stigma tools developed specifically for healthcare workers (initial review and qualitative work now published as Kuhlmann et al.[92] and Danqa et al.[93]; tool development ongoing). Finally, there is already a substantial separate body of stigma-related research focused on healthcare workers' experiences, likely due to their accessibility as a study population compared to many other stigmatised groups. Where I do highlight healthcare worker-specific experiences (e.g. in qualitative data in Chapter 3), I have attempted to do so in a proportionate manner.

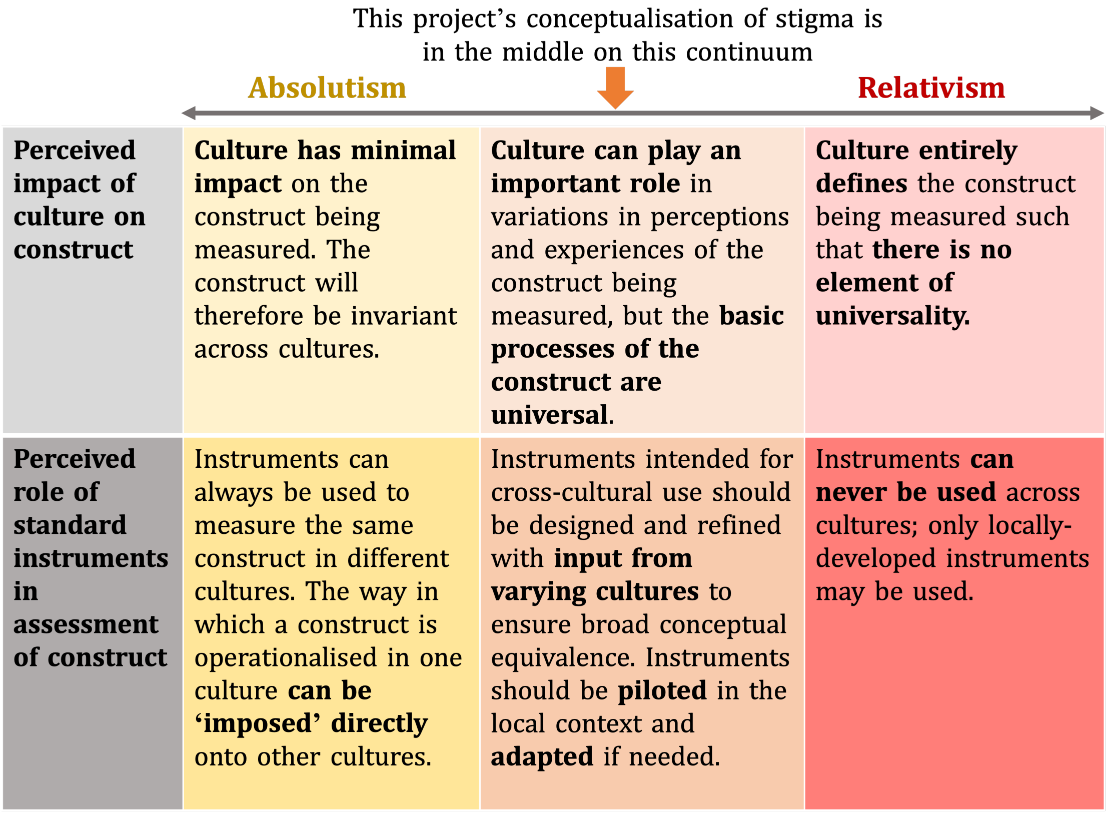
Lastly, since the definition of an infectious disease outbreak is a rapid and unexpected rise in disease case numbers, established, endemic diseases such as HIV and tuberculosis are beyond the focus of this work. Within this thesis, the term outbreak is used broadly to encompass events of varying scale, including epidemics and pandemics.

1.4.2 Research paradigm

In this thesis I adopt the research paradigm of critical realism. Critical realism recognises social phenomena such as stigma as components of reality.[94,95] It acknowledges that these phenomena emerge from human action and can shape (but do not necessarily determine) action in return.[96] It also emphasises the importance of unseen complex mechanisms, such as trust and power dynamics, in determining observable events.[94,95] Through this, it facilitates an understanding of stigma that considers broader societal structures rather than exclusively focusing on individual attitudes and behaviours.

A critical realist inquiry seeks to understand a social phenomenon and its underlying causes through observable features.[95] This process usually involves capturing people's perceptions and experiences, and then using these to develop and test conceptualisations or theories.[95] These theories are not objective truths – they are fallible and likely to vary – but are considered useful, and can be refined through testing.[95–97] Critical realism supports the use of different methods, provided they help build understanding,[97] and has been widely used in research seeking to identify the underlying causes of societal problems and support practical change.[95]

As a philosophical approach, critical realism sits between the traditional paradigm poles of positivism and constructivism.[97] When applied to conceptualising stigma, those who adopt a positivist research paradigm would take an 'absolutist' approach to the construct of stigma.[98] In contrast, constructivists would take a 'relativist' approach to stigma.[98] The paradigm of critical realism is positioned somewhere between these. The differences in these conceptualisations are explained in Figure 1.4.



This project's conceptualisation of stigma is
in the middle on this continuum

	Absolutism		**Relativism**
Perceived impact of culture on construct	**Culture has minimal impact** on the construct being measured. The construct will therefore be invariant across cultures.	**Culture can play an important role** in variations in perceptions and experiences of the construct being measured, but the **basic processes of the construct are universal**.	**Culture entirely defines** the construct being measured such that **there is no element of universality.**
Perceived role of standard instruments in assessment of construct	Instruments can always be used to measure the same construct in different cultures. The way in which a construct is operationalised in one culture **can be 'imposed' directly** onto other cultures.	Instruments intended for cross-cultural use should be designed and refined with **input from varying cultures** to ensure broad conceptual equivalence. Instruments should be **piloted** in the local context and **adapted** if needed.	Instruments **can never be used** across cultures; only locally-developed instruments may be used.

Figure 1.4: Continuum of assumptions about the influence of culture on complex constructs. Figure content based on Herdman et al.[98]

1.4.3 Reflexivity

Reflexivity is a process that requires researchers to explicitly examine how their backgrounds, social identity, and emotional responses influence their work.[99] It is considered particularly important in global health research due to the power dynamics, cultural differences, and sensitivities that often characterise this work.[100,101]

I am a South African clinician with a master's degree in global health. I undertook this work in a team that conducts outbreak-related clinical research, with a focus on developing standardised data collection tools and core outcome sets. While I have engaged with social sciences literature and undertaken training in methods such as psychometric analysis for this project, my disciplinary grounding and team's remit have informed the project's framing. This thesis therefore adopts an applied policy- and practice-oriented perspective, rather than exploring the psychological or sociological depths of stigma.

Before moving to Oxford, I was a frontline worker in South Africa's first COVID-19 referral centre. Early in the pandemic, I observed patients and colleagues avoiding testing and contact tracing or travelling outside of their communities to anonymously seek care. In a district with an estimated HIV prevalence of 36%,[102] these behaviours were concerningly familiar. The patterns prompted my interest in the psychosocial and public health consequences of stigma. The initial idea for this research originated independently from a patient and public involvement event organised by my research team. However, my observations of stigma in the South African context influenced how I designed, conducted, and interpreted the research.

Although I did not detail my clinical background in participant-facing documents, it was often directly asked about or inferred from my title. This background facilitated my understanding of medical and operational jargon in interviews and meetings with outbreak responders, supporting free-flowing conversation. However, it may have discouraged interviewees with lived experience from discussing stigmatising interactions with healthcare workers.

I am an outsider to the communities this research was conducted in and, apart from having COVID-19 early in the pandemic, I have no personal experience of the outbreak-related illnesses or stigma explored in this thesis. My perspective on the topic was therefore that of an external observer. This provided analytical distance but limited my insight into lived realities. I tried to approach the work with sensitivity to these dynamics. This involved seeking guidance and input from local collaborators and people with lived experience on the research objectives, participant-facing documents, data collection methods, and interpretation of findings. I have also taken care not to overstate my understanding of cultural beliefs and traditions.

As a white researcher affiliated with a well-resourced British university, my positionality is equally one of privilege and historical power. Even in Uganda, which is geographically and contextually closer to my home than Oxford, I was predominantly perceived as a researcher from England. I tried to be attentive to how this could affect relationships with collaborators and participants. In particular, I am aware that these associations carry a legacy of extractive research. With this in mind, I tried to prioritise capacity building within the research process and share outputs with communities and stakeholders in ways that support meaningful change. It has also been important that the data are co-owned by local organisations.

For fieldwork in central Uganda, local collaborators noted that white researchers are associated with health emergencies and could draw attention, especially when visiting Ebola survivors. I therefore mostly conducted interviews in a pharmacy and two health centres with participants who opted for English interviews, while local data collection teams conducted community-based interviews. Multiple components of this work also involved stakeholder and expert consultation. In recruiting for these processes, my institutional affiliation enabled access to senior experts, but meant I was more likely to approach contacts within established, UK-affiliated networks.

I maintained a set of informal reflexive notes throughout this research. These trace my evolving understanding of stigma, but also the challenges of the work. I found peer and professional debriefing sessions helpful in processing emotion-laden data, enabling me to neither avoid nor overemphasise this content in outputs.

2

Systematic review of existing stigma scales

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2.1 Chapter preface

2.1.1 Overview

This chapter presents a systematic review of scales that have been used to assess stigma in infectious disease outbreaks. The review analyses the range, content, and methodological quality of these tools, highlighting patterns in their development and common gaps in psychometric assessment. The findings point to inefficiencies in the current approach to outbreak-related stigma assessment, informing recommendations for future scale design.

2.1.2 Publication and contributions

This chapter contains content from the following publication:

- **Paterson A**, Cheyne A, Jones B, Schilling S, Sigfrid L, Stolow J, et al. Systematic review of scales for measuring infectious disease–related stigma. *Emerging Infectious Diseases.* 2024.

For this component of work, I took responsibility for study design, screening and selection of studies, data management and analysis, and drafting of the initial manuscript. A research librarian from the Bodleian Health Care Libraries, Nia Roberts, provided input on the search strategy. A second reviewer with systematic review experience, Benjamin Jones (BJ), assisted with double-screening studies, and my supervisor, Ashleigh Cheyne (AC), verified extracted data.

2.2 Introduction

2.2.1 Background

Robust stigma assessment is an important foundation for ensuring effective stigma reduction.[90] It enables better understanding of the dimensions of stigma, its extent or severity in a given setting, and any changes over time.[89] These data can guide interventions and policy decisions to reduce stigma and monitor progress.

A common approach to stigma assessment involves the use of scales. A scale is a set of closed-ended survey items that form a composite score.[81] Scales are widely used in health and behavioural research to measure latent constructs — that is, social or psychological phenomena such as attitudes, beliefs, or norms that cannot be directly observed or captured by a single question.[81] Instead, these constructs are inferred through a series of scale items, each addressing a different aspect of the concept. When combined, these items provide a more comprehensive approximation of the underlying construct than any individual question could. The use of multiple items also allows for reduction of measurement error, improving the reliability of results.[81] Well-designed scales are central to much of our understanding in public health, underpinning work on patient-reported outcomes, social determinants of health, and intervention evaluation.[81,103] However, ensuring that scales accurately capture the intended construct presents a methodological challenge.[81]

The field of psychometrics seeks to address this challenge, and provides the theoretical and methodological basis for evaluating measurement properties such as validity and reliability.[104] Extensive technical guidance has been produced to support the psychometric development and evaluation of scales. This includes a step-by-step guide developed by Boateng et al.[81] and the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN), which outline detailed criteria for scale evaluation.[105,106]

Despite this guidance, robust scale development and validation remain demanding tasks, requiring substantial time, funding, and participant attention.[81] The time-intensive nature of scale development can be illustrated using the example of a thyroid-related quality of life measure, ThyPRO. This measure originated from doctoral work in 2007, with construct validity, reliability, and responsiveness studies published between 2009 and 2014.[107–110] A refined short form was subsequently released in 2015,[111] and a study establishing minimal important change published in 2021.[112] This demonstrates how the development and validation of a high-quality instrument can span well over a decade.

As a result of the demanding nature of robust scale development, many incomplete or poorly validated scales are used across disciplines. For example, a review of 400 mental health-related stigma scales found that two thirds of scales had not undergone any systematic psychometric evaluation.[113] The resource constraints that make scale development and evaluation difficult in ordinary circumstances are heightened in outbreak contexts due to limited timeframes and competing demands.

There are also important conceptual tensions involved in developing and applying stigma scales. Reviews of scales used to assess stigma across chronic conditions have noted considerable overlap in content.[89,90] This supports a less siloed, disease-specific approach to stigma assessment.[89,90] Such an approach would enable greater reuse of scales, expanding the data available for psychometric testing. It would also reduce the need for *de novo* scale development, saving time and resources. However, since stigma is a social construct, scale items may not carry the same meaning across all settings. It is therefore important to ensure cultural relevance and contextual fit in different settings.[90] Outbreak contexts heighten this tension, as the cultural and social environments of future outbreaks are uncertain and likely dynamic. Scales must therefore be readily adaptable if they are intended for reuse in future outbreak settings.

2.2.2 Objective and research questions

This chapter addresses the first objective of the thesis by systematically reviewing scales used to assess outbreak-related stigma. In doing so, it seeks to answer the following questions:

- What scales have been used to measure stigma due to outbreaks in affected communities to date?
- What are the content themes within these scales?
- What methods were used to develop and validate these scales?
- What are the psychometric properties (i.e. validity and reliability) of these scales?
- How transferable are these scales to different outbreak contexts and populations?
- What are the limitations in the development, validation, and use of these scales?

2.3 Methods

2.3.1 Study design and reporting standards

This review was informed by the COSMIN guideline for systematic reviews of patient-reported outcome measures.[105] The methods were prospectively registered

(International Prospective Register of Systematic Reviews (PROSPERO) record number CRD42023396387).

The methods and findings are reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 checklist.[114]

2.3.2 Rationale for methods

A systematic review was conducted for this objective as it enabled structured synthesis of existing tools while incorporating formal quality appraisal.[115] Alternatives considered, such as a rapid or scoping review, were less suited to psychometric evaluation and less compatible with established resources for reviewing scales, such as the COSMIN guideline. Framework synthesis was used to explore scale content, as it offered an efficient means of identifying anticipated and emerging themes across discrete data sources (in this case individual scales).[116]

2.3.3 Search strategy

To identify relevant studies, a search strategy combining terms for 'stigma', 'infectious disease outbreaks', and 'scales' was applied across the Cochrane Library, MEDLINE, PsycINFO, EMBASE, Global Health, and Web of Science databases (Appendix A.1). The search was run on 31 January 2023 without date or language restrictions. Reference lists of included studies and relevant systematic reviews were also screened.

2.3.4 Eligibility and study selection

All records were assessed according to the eligibility criteria detailed in Table 2.1.

Table 2.1: Systematic review eligibility criteria

Criteria	Inclusion	Exclusion
Population	Includes community members of any age or gender, with or without personal experience of the illness	Focuses exclusively on healthcare workers (as per the project scope detailed in Chapter 1)
Concept	Describes the development, validation, or use of a scale designed to measure outbreak-related stigma	Focuses on stigma occurring during an outbreak period, but not due to the outbreak (e.g. studies that assessed race-based discrimination in 2020/2021 without investigating whether it was linked to COVID-19)
Context	Pertains to infectious disease outbreaks	Pertains exclusively to non-communicable or established infectious diseases
Types of studies	Cross-sectional or cohort studies; studies describing scale development, piloting, or validation; and interventional studies that incorporate a pre-intervention survey	Interventional studies without a pre-intervention survey; studies investigating stigma solely through qualitative methods; protocols, guidelines, book sections, case reports, opinion pieces, conference abstracts, preprints, and unpublished literature
Minimum validity of scale	Uses stigma scales that have been assessed, at minimum, for face validity (i.e. at least superficially reviewed by potential end-users or experts to confirm that they reflect the concept of stigma[105])	—

All retrieved citations were uploaded to EndNote 20.5[117] to identify and remove duplicates. Following deduplication, the remaining citations were uploaded to Rayyan systematic review software to facilitate structured study selection.[118]

To ensure consistency, a random 10% of titles and abstracts were independently screened by a second reviewer (BJ). Inter-rater reliability was assessed using Cohen's kappa, with discrepancies resolved through discussion, and the eligibility criteria refined as needed. This process was repeated until Cohen's kappa indicated 'excellent' agreement ($\kappa \geq 0.75$), after which the remaining records were divided between reviewers.[119]

Eligible full texts were screened using the same process. The required level of agreement was achieved following the second round of title and abstract screening ($\kappa = 0.76$) and the second round of full text screening ($\kappa = 0.82$). Where complete scales were not available, corresponding authors were emailed to request access. If the scale was still not provided, the study was excluded. Stigma scales were professionally translated into English when necessary. Where multiple articles described the same study, the article containing the most information on the relevant stigma scale was selected.

2.3.5 Data extraction and analysis

Data extraction was conducted using Microsoft Excel.[120] An additional reviewer (AC) independently extracted a random 10% of the data to ensure consistency, with no discrepancies observed in the extracted data. The following information was extracted for each publication: first author, year of publication, scale name, outbreak and country setting, language of administration, methods of scale development and validation, scale items, reported psychometric indicators (e.g. Cronbach's alpha), study population, sample size, and mode of administration.

Descriptive statistics were used to analyse the characteristics and distribution of unique scales. A scale was considered unique if it differed from any other included scale in at least one of the following aspects: number of items, item phrasing (excluding minor translation differences), or dimensional structure.

Framework synthesis was used to identify the domains of stigma included in the scales.[116] This method combines deductive and inductive approaches to analyse extracted qualitative data, and is frequently applied in health-related reviews.[116] It begins with an initial conceptual framework, which provides the basis for coding the data.[116] Additional themes (in this case, stigma domains) are then generated from content not captured by the original framework, resulting in a revised framework.[116]

A stigma typology developed by Jones and Corrigan[14] served as the initial framework for coding the extracted scale items (Appendix A.2). This framework was adjusted throughout the analysis as new domains emerged. For example, many scales included questions about stigma from a partner or one's family, but these questions did not fit into the existing categories of public, self, structural, or anticipated stigma. A separate 'social stigma' category was therefore added to the framework. Each scale item was assigned to at least one stigma domain.

The psychometric quality of each scale was assessed using the COSMIN guidelines, focusing on validity and reliability (see Table 2.2 for definitions). The transferability of each scale was assessed using the Cross-Cultural Equivalence Framework described by Stevelink and van Brakel[121] (Appendix A.3).

Table 2.2: Definitions of psychometric properties

Domain	**Property**	**Aspect of property**	**Definition**
Validity	Content validity		The degree to which the content of an instrument is an adequate reflection of the construct to be measured
		Face validity	The degree to which an instrument looks as though it reflects the construct to be measured
	Construct validity	Internal (structural) validity	The degree to which the scores of an instrument are an adequate reflection of the dimensionality of the construct to be measured
		External construct validity (hypothesis testing)	The degree to which the scores of an instrument are consistent with hypotheses on relationships to scores of other instruments
		Cross-cultural validity	The degree to which an instrument accurately measures the same construct in different population groups.
	Criterion validity*		The degree to which the scores of an instrument are an adequate reflection of a 'gold standard'

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Table 2.2 – continued from previous page

Domain	Property	Aspect of property	Definition
Reliability	Internal consistency		The degree of interrelatedness among the items
	Test-retest reliability		The degree to which scores remain stable when a measurement is repeated under stable conditions
	Measurement error		The systematic and random error of a respondent's score that is not attributed to true changes in the construct to be measured
Responsiveness			The ability of an instrument to detect change in the construct to be measured over time

*Criterion validity was not considered in this review as there is no gold standard for stigma assessment.

Table adapted from COSMIN definitions of domains, measurement properties, and aspects of measurement properties.[104]

2.3.6 Quality assessment

The quality of each study was assessed using the COSMIN Risk of Bias Checklist.[106] This checklist uses a modular approach that accounts for whether the study was intended for scale development or validation, and what aspects of a scale the study set out to validate.[106] The quality of each method is rated separately using a 'worst score counts' principle.[106] The checklist considers the quality of a study distinct from the quality of scales used within the study: a high quality study has a low risk of bias, while a high quality scale has good measurement properties.[105] For each scale, the quality and number of studies assessing the same measurement property are synthesised to determine the overall certainty of the rating for that property.[105]

2.4 Results

The search strategy retrieved 12,879 records after deduplication. The majority of these records were excluded at title and abstract screening as their use of the search term ‘discriminat*’ referred to the discriminatory ability of prediction models, rather than social discrimination. Forty-one studies met the inclusion criteria, describing the development, validation, and/or use of 43 unique outbreak-related stigma scales (Figure 2.1).

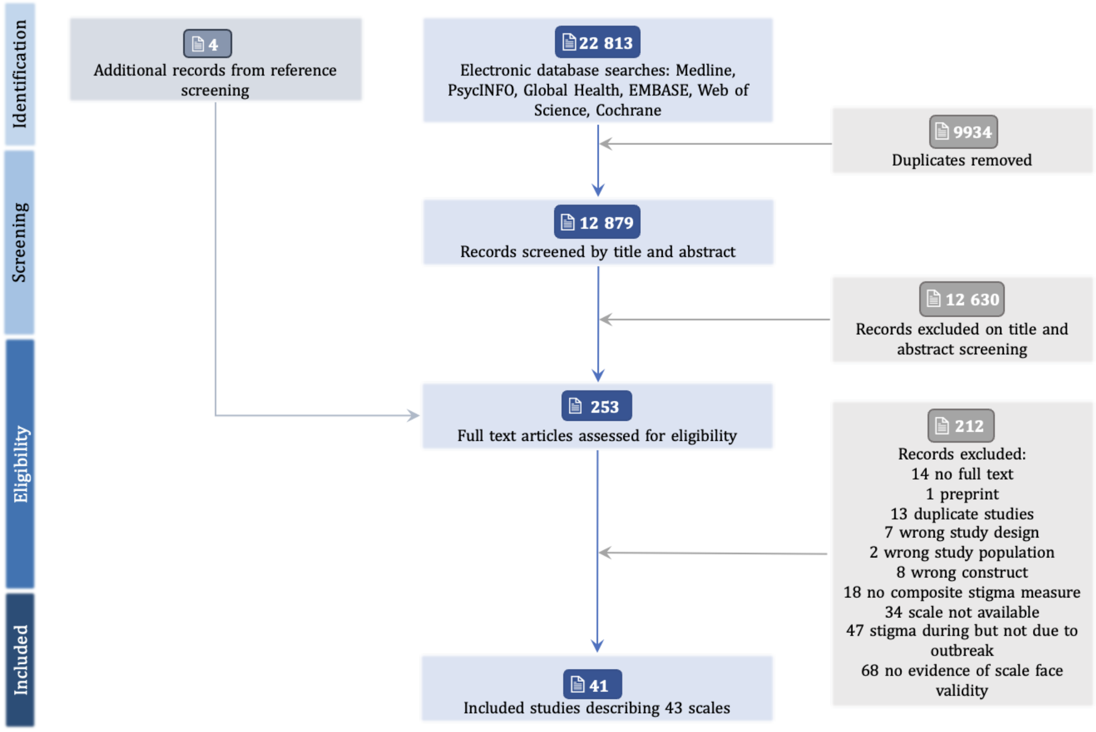

Figure 2.1: PRISMA flow diagram

2.4.1 Overview of stigma scales

Of the 43 included scales, 42 (98%) were newly developed for the outbreaks they were used in. Thirty-eight of the included scales (88%) had only been used once in the published literature. The scales were used across 27 countries (Appendix A.4).

Thirty-three scales (77%) focused on COVID-19-related stigma, seven (16%) assessed Ebola disease-related stigma, two (5%) were SARS-related, and single scales (2%) were used for Lassa fever and Zika virus disease stigma. Initial publication of these scales occurred a median of 25 months after the first case of a given outbreak (interquartile range: 18-30 months).

Almost half of the scales (21 scales, 49%) were developed based on HIV literature and existing HIV stigma scales (Appendix A.4). Only nine scales (21%) included primary qualitative data in their scale development processes. The *Long COVID Stigma Scale*, described by Pantelic et al.,[122] was the only scale explicitly co-designed with affected community members.

2.4.2 Content of scales

Twenty-one domains of stigma were identified in the included scales through framework synthesis. These domains reflected three overarching forms of stigmatising response: prejudice (endorsement of negative stereotypes), discrimination (unfair treatment), and medically unwarranted avoidance (interpersonal avoidance beyond public health advice). These were enacted by a range of actors (Table 2.3). Several scales also captured pre-emptive concerns or behaviours to avoid future stigma (anticipated stigma) and stigma towards individuals associated with the disease but without personal experience of the illness (stigma-by-association).

Table 2.3: Definitions and example scale items for each stigma domain identified in the framework synthesis

	Prejudice *(endorsement of stereotypes)*	**Discrimination** *(differential treatment)*	**Medically unwarranted avoidance** *(distancing beyond health advice)*
Social *(stigma from family and friends)*	"I feel blamed by relatives or friends" - *Self-stigma Scale (SSS-15)*[123]	"Neighbours and others have prevented you from returning to your home" - *Stigmatisation related to EVD and COVID-19 scale*[54]	"People I care about stopped calling after learning I have COVID" - *Modified 12-item HIV Stigma Scale*[124]
Public *(stigma from broader society)*	"Most people think that a person who has had Ebola is disgusting" - *Ebola-related Stigma Survey*[125]	"I am treated unfairly in areas of public life" - *COVID-19 Experienced DISCrimination Scale (CEDISC)*[126]	"I keep a physical distance once I find out that someone has had COVID-19 even if he/she is recovered" - *Public Attitudes towards Stigma Questionnaire*[127]
Workplace *(stigma from colleagues and employers)*	"My feeling of job security has been affected by my illness" - *COVID-19 Perceived Stigma Scale-22 (CPSS-22)*[128]	"I will dismiss my employee who recovers from COVID-19" - *Social stigma and discriminatory attitudes scale*[129]	"Someone refused to buy products from you" - *Stigmatisation related to EVD and COVID-19 scale*[54]
Provider-related *(stigma from service providers)*	"You feel it is not worthwhile for you to serve persons who contracted COVID-19" - *Stigma Discrimination Scale (SDS-11)*[123]	"[I was] treated unfairly by healthcare professionals" - *COVID-19 Experienced DISCrimination Scale (CEDISC)*[126]	"In the hospital or clinic, I was totally ignored by healthcare staff" - *Ebola-related stigma instrument*[130]
Structural *(stigma from institutional practices and policies)*	N/A	"The first COVID-19 patient in each city should be identified and penalised due to their role in spreading the disease" - *COVID 19-related enacted Stigma Questionnaire*[131]	"Survivors of COVID-19 should be isolated from other people." - *Perceived Stigmatization of COVID-19 Scale*[132]
Self *(internalisation of stigma)*	"Having had COVID-19 infection makes me feel that I am a bad person" - *COVID-19-related Stigma Survey*[133]	"I stopped eating with other people" - *Ebola-related stigma instrument*[130]	N/A

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Table 2.3 – continued from previous page

	Prejudice *(endorsement of stereotypes)*	**Discrimination** *(differential treatment)*	**Medically unwarranted avoidance** *(distancing beyond health advice)*
Anticipated *(disclosure concerns or avoidance due to fear of stigma)*	“I worry that people may judge me negatively when they find out I have long Covid” - *Long COVID Stigma Scale (LCSS)*[122]	“You have avoidance behaviours such as staying home for fear of being stigmatised or rejected” - *Stigmatisation related to EVD and COVID-19 scale*[54]	N/A
Stigma-by-association *(stigma due to societal association with the disease without personal experience of the illness)*	“If they knew about it would your neighbours, colleagues or others in your community think less of your family because of your COVID-19 infection?” - *Arabic Explanatory Model Interview Catalogue (EMIC)*[134]	“A school refused to accept your children” - *Stigmatisation related to EVD and COVID-19 scale*[54]	“If a person was infected with COVID-19, it is better to avoid his/her family members” - *Community COVID-19 Stigma Scale*[135]

Framework based on Jones and Corrigan stigma typology.[14]
COVID-19 = Coronavirus disease 2019; EVD = Ebola virus disease; N/A = Not applicable.

The most commonly assessed stigma domains were public prejudice, public discrimination, and self prejudice. In contrast, provider-related, workplace, and anticipated prejudice were infrequently included (Figure 2.2).

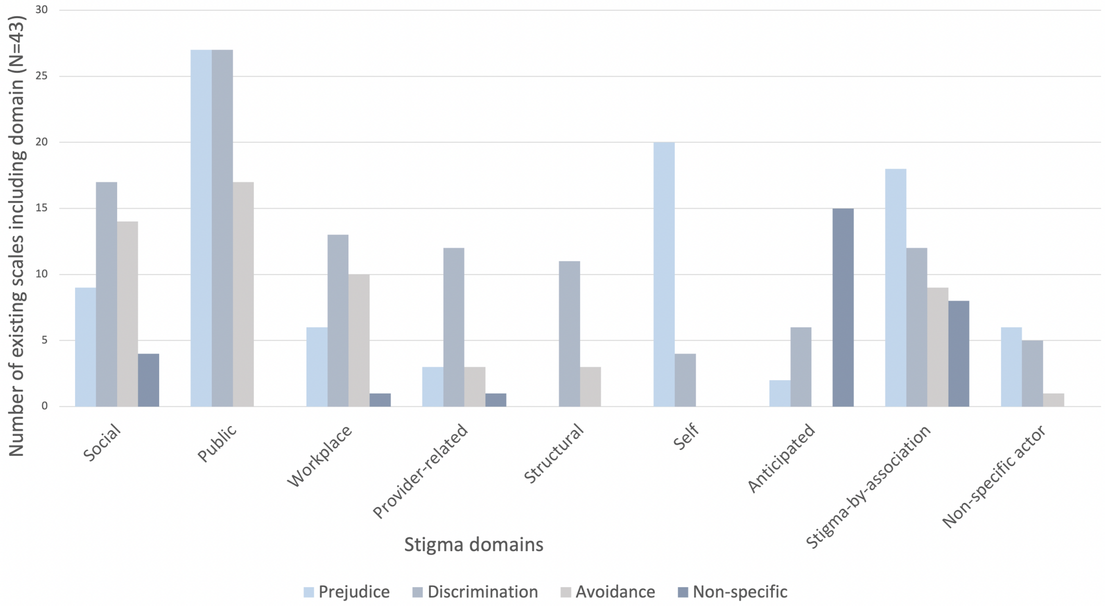

Figure 2.2: Frequency of inclusion of stigma domains in existing scales

A third of the scales (14 scales, 33%) included items that deviated from widely accepted definitions of stigma (as set out in Chapter 1). These scales considered adoption of recommended preventive measures (e.g. “People should stay away from those infected with COVID-19”) and limited knowledge of a disease (e.g. “COVID-19 only affects the elderly”) as evidence of stigma.

Sixteen scales (37%) asked participants if they endorsed or participated in stigmatisation of others, 15 scales (35%) asked about participants’ own experiences of stigma, and four scales (9%) enquired about participants’ observations or perceptions of stigma in their community. Eight scales (19%) included items from a mixture of these perspectives.

2.4.3 Psychometric properties of scales

Psychometric evaluation of scales was limited. Among the scales that underwent validation, none consistently met the COSMIN criteria for sufficient validity and reliability for the properties assessed (Appendix A.5).[105]

Approximately half of the scales (24 scales, 56%) were reviewed by relevant professionals and community members prior to administration. Only three studies[124,128,135] (7%) reported formal content validity scores. According to the COSMIN criteria all scales had indeterminate or inconsistent content validity.

The structural validity of 18 scales (42%) was tested, with 13 of these scales (72%) meeting the criteria for sufficient validity. Five scales (12%) were evaluated for external construct validity using hypothesis testing, all of which met the sufficiency criteria. Seven scales (16%) were assessed for test-retest reliability, with three (43%) deemed sufficient. No studies assessed responsiveness.

Internal consistency was reported for 33 scales (77%), mostly using Cronbach's alpha coefficients. However, the structural validity of a scale needs to be confirmed before internal consistency can be tested.[105] As a result, only 13 (39%) of these scores could be considered further. Of these 13 scales, 12 (92%) had sufficient internal consistency.

2.4.4 Transferability of scales

Only one scale, the *Stigmatization related to EVD and COVID-19 Scale* developed by Cenat et al.,[54] was used across different disease outbreaks. However, this scale was not publicly available and had to be requested. In addition, the *COVID-19-related Stigma Survey* administered in India[133] and Bangladesh[136] is closely related to the *Ebola-related Stigma Scale* administered in Liberia[125] and adopted 14 of the original scale's 16 items. Three scales (7%) were administered in more than one country. Six scales (14%) were used across different participant profiles (i.e. community members with and without lived experience of the disease).

No scales had sufficient documented evidence of cross-cultural transferability when reviewed using a cross-cultural equivalence framework (Table 2.4).[121]

Table 2.4: Transferability of scales

Stigma scale name	**Cross-national**	**Cross-outbreak**	**Participant profiles†**
COVID-19 stigma scales			
COVID-19-related Stigma Survey[133,136]	■	□	□
COVID-19 Stigma Scale[135,137]	▨	▨	□
Community COVID-19 Stigma Scale[135,137]	▨	▨	□
Eight-item Stigma Scale[138]	▨	□	□
Arabic Explanatory Model Interview Catalogue (EMIC)[134]	▨	▨	□
COVID-19 Stigma Instrument-Patients (CSI-P2)[139]	□	□	□
The Perceived Courtesy Stigma Sub-scale[140]	▨	□	▨
The Affiliate Stigma Sub-scale[140]	□	▨	□
Modified 12-item HIV Stigma Scale[124]	▨	□	□
Stigma Discrimination Scale (SDS-11)[123]	▨	□	■
Self-stigma Scale (SSS-15)[123]	□	□	□
COVID-19 bullying scale[141]	▨	▨	■
COVID-19 Experienced DISCrimination Scale (CEDISC)[126]	▨	▨	□
COvid-19 INternalised Stigma Scale (COINS)[126]	▨	▨	□
COVID-19 Responsibility Attribution scale[142]	□	□	□
COVID-19 Attitudes scale[142]	□	□	□
COVID-19-related enacted Stigma Questionnaire[131]	□	□	□
Discrimination in Medical Settings Scale[143]	▨	▨	□
30-item Bullying during the COVID-19 Pandemic Questionnaire[144]	□	▨	▨
Stigmatising Attitudes Scale[145]	□	□	□
COVID-19 Stigma Scale (COVID19SS)[146]	□	▨	▨
COVID-19 Perceived Stigma Scale-22 (CPSS-22)[128]	▨	▨	□
Public Attitudes towards Stigma Questionnaire[127]	□	□	□

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Table 2.4 – continued from previous page

Stigma scale name	Cross-national	Cross-outbreak	Participant profiles[†]
Perceived Stigmatization of COVID-19 Scale[132]	□	□	□
Public COVID-19-related Stigma towards Patients Measure[147]	▒	▒	▒
Public COVID-19-related Stigma towards Wuhan People Measure[147]	□	□	▒
COVID-19 Public Stigma Scale[57]	▒	□	□
Social stigma and discriminatory attitudes scale[129]	▒	▒	□
Modified Measure of Disease-Related Stigma (MDRS) Scale[148]	□	□	□
The Social Stigma Scale[149]	□	□	□
COVID-19 related Social Stigma Scale[150]	□	□	□
Long COVID Stigma Scale (LCSS)[122]	▒	□	□
Ebola disease stigma scales			
Ebola-related Stigma Scale[125]	▒	□	□
7-item EVD-related stigma index[60,151]	▨	▒	▨
Ebola-related stigma instrument[130]	□	▒	□
EVD-related stigma scale[61]	□	▒	▨
Stigma toward EVD Survivors Scale[152]	▒	▒	▒
EVD Stigma Index[153]	▒	▒	□
SARS stigma scales			
SARS Social Life and Services Stigma Self-report Questionnaire[52]	□	□	▨
SARS Discrimination in the Workplace Self-report Questionnaire[52]	□	□	▨
Zika Virus Disease stigma scales			
Modified Version of the Knowledge, Attitudes, and Practices Survey Tool on Zika Virus Disease[154]	▒	▒	▒
Lassa fever stigma scale			
Lassa fever-associated stigmatization scale[72]	▒	□	▒
Stigma scales used across multiple diseases			
Stigmatization related to EVD and COVID-19 scale[54–56]	▨	▨	□

*Evidence of cross-cultural transferability assessed using Stevelink and van Brakel's Cross-Cultural Equivalence framework[121] (Appendix A.3). [†]Usability for persons with and without a personal history of the disease. COVID-19 = Coronavirus disease 2019. EVD = Ebola virus disease; SARS = Severe Acute Respiratory Syndrome.

Key:

■ Used with good cross-cultural equivalence

□ Not used: appears readily usable

▨ Used with indeterminate or mixed cross-cultural equivalence

▒ Not used: would require substantial adaptations

2.4.5 Quality of studies

The quality of seven (20%) of the 35 studies describing scale development received a 'doubtful' quality rating for these methods, with the remaining studies rated as 'inadequate' according to the COSMIN Risk of Bias Checklist (Appendix A.4).[106] Studies which aimed to content validate an existing scale had similar ratings. Structural validity, test-retest reliability, and hypothesis testing methods more commonly received 'very good' or 'adequate' quality ratings but were infrequently conducted. Of the 33 studies assessing internal consistency, 20 (61%) were rated 'doubtful' due to no prior evidence of structural validity.

2.5 Discussion

This review found that numerous scales have been developed to assess outbreak-related stigma and used in a range of geographical settings. However, shortcomings in the development, validation, and use of these scales mean that outbreak-related stigma is being incompletely and unreliably assessed.

2.5.1 Psychometric quality of existing scales

The quality of scale development and content validation methods were rated inadequate or doubtful for all studies according to the COSMIN Risk of Bias Checklist. This is particularly concerning since COSMIN considers content validity the most important measurement property, specifying that if a measure has insufficient content validity it should not be recommended for use.[103] Several other forms of psychometric assessment (e.g. external construct validity) were not performed on the majority of scales. This may be due to the urgency of an outbreak resulting in short-cutting best practices. Unfortunately, these shortcuts compromise the validity of study findings.

Of the scales reviewed, *The Perceived Courtesy Stigma Scale* and *The Affiliate Stigma Scale*, both developed by Li et al.,[140] had the most evidence of sufficient validity and reliability. However, these scales were only designed to assess stigma towards people without personal experience of the disease, and require further assessment of content validity and transferability.

2.5.2 Content of existing scales

Scales were broadly similar in content, with almost half derived from similar HIV-related stigma scales. Despite this, there was a notable lack of repeated use of these scales across diseases and settings. This is a missed opportunity to maximise on scale development efforts, strengthen the evidence base for scale use, and expand understanding of common manifestations of stigma across outbreaks.[34,89,155]

The fact that many of the scales were derived from HIV-specific content also raises concerns about their validity when applied to acute outbreaks. For example, stigma-by-association questions specific to sexual partners or groups at increased risk of HIV may not be relevant to COVID-19. Similarly, questions about avoidance may not account for mandated isolation of affected persons in acute outbreak settings. This could explain the misuse of items such as “People should stay away from those infected with COVID-19” and other key preventive measures as markers of stigma in over a quarter of scales. This misuse could be minimised through the use of theoretical frameworks and qualitative data in scale design, and formal content validity scoring processes.[81,103]

Stigma scales tended to capture more advanced forms of stigma such as public discrimination and the internalisation of persistent stigma (i.e. self stigma). There was poor detection of potential precursors to these forms of stigma (e.g. social, workplace, or provider-related prejudice). This is of consequence because, if identified, these could be addressed ‘upstream’, reducing the detrimental effects of stigma on wellbeing and outbreak control.[90]

In addition, the high frequency of stigma-by-association items in the scales demonstrates that community members without personal experience of the relevant diseases are not only potential ‘stigmatisers’, but may also be stigmatised themselves. This highlights a limitation of current practice, which often creates a false dichotomy by giving individuals who have had the disease scales about stigma experiences, and other community members scales asking about endorsement of stigma. Instead, any given individual can be both a ‘stigmatiser’ and stigmatised.[25] This issue could be overcome by using items that are distanced from the respondent (i.e. less personal) such as case vignettes or questions about third-person observations.[134] These allow all community members (regardless of disease status) to answer a wider range of questions while reducing social desirability bias. Another option, illustrated in the HIV PopART trial,[156] is to use multiple scales in parallel to separately ask people with lived experience and other community members about both experienced and endorsed stigma and then triangulate findings.

2.5.3 Complexities of scale development in outbreaks

The median time from the start of an outbreak to publication of a relevant stigma scale was two years. This can be partially attributed to the slow peer-reviewed publication process, but also reflects the amount of time required for scale development. As a result, outbreak-related stigma is often investigated retrospectively, rather than early in an outbreak, when it has the greatest potential to inform outbreak response, and when stigma may be heightened due to isolation and uncertainty.[40,52]

2.5.4 Implications for research and practice

Together, these findings demonstrate that the model of *de novo* stigma scale development for each context is not effective for infectious disease outbreaks. It leads to overlapping, methodologically limited, and slow outcomes, despite the best intentions of developers. An innovative approach is needed to overcome this challenge.

The findings support the pre-emptive development of a methodologically rigorous stigma scale which can be easily adapted for new outbreaks. This would allow outbreak responders to integrate stigma assessment into surveillance activities at the onset of an outbreak, facilitate cross-learning, and reduce duplication of efforts. Additional recommendations for future scale design, validation and use are provided in Table 2.5.

Table 2.5: Recommendations for future outbreak stigma scale design, validation, and use

Scale design recommendations
A theoretical framework should be applied from scale conception to ensure representation of all relevant stigma domains.
Scales should be co-designed with people with lived experience of outbreak-related stigma.
When resources allow, scale design should be informed by a range of outbreak diseases and settings to enhance transferability. This could be facilitated by international public health institutions or consortia.
Established best practices should be followed when translating and adapting scales for new settings.
Scale validation recommendations
Items should be formally assessed for relevance and comprehensiveness by experts in the field and potential respondents.
Confirmation of the structural validity of scales should precede internal consistency testing.
External construct validity, test-retest reliability, and responsiveness of scales should be assessed to confirm suitability for evaluating interventions.
The cross-cultural validity of scales should be assessed when used for comparison across settings or populations.

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Table 2.5 – continued from previous page

Scale use recommendations
Scales should be used in longitudinal and pre-post interventional studies to assess stigma trends over the course of an outbreak.
When possible, representative sampling should be adopted in administration of stigma scales.
The results of studies assessing stigma in outbreaks and the scales used need to be publicly disseminated in a timely manner with minimal access barriers such as paywalls.
Scales without evidence of content validity should not be used without further validation.

While this review identifies multiple areas for improvement, it also highlights the substantial methodological and logistical challenges of rigorous stigma scale design, particularly in outbreak contexts. Social and behavioural research is often under-resourced compared to other outbreak-related disciplines,[157] and the compressed timelines and competing priorities in outbreaks constrain the feasibility of psychometric evaluation. These realities must be accounted for when considering the existing scales and formulating future directions.

2.5.5 Strengths and limitations

This review provides a comprehensive summary of the uses, validity, and transferability of existing outbreak stigma scales. These data can be used to improve the validity and versatility of future outbreak-related stigma scales. The application of the COSMIN framework provided a structured and transparent method for evaluating measurement properties, enabling comparability across diverse instruments. The review avoided pooling or statistically comparing heterogeneous stigma outcomes, which has been a focus, and limitation, of previous systematic reviews on the topic.[158,159]

There are also limitations to this review. The screening strategy relied on inclusion of stigma or a similar term in the title or abstract. Studies that used a stigma scale but did not report this in their abstract may have therefore been missed. This review also did not include healthcare worker specific scales, which may more frequently include workplace stigma items.

Furthermore, while the COSMIN criteria are widely used for evaluating scale quality, they are primarily designed for patient-reported outcome measures. Some requirements may have therefore been overly stringent and less suited to scales measuring stigma at a population level. For example, ensuring representation of the full sampling frame in initial development phases may be more difficult, particularly in an outbreak. The scale content validity criteria also only recognise inductive scale development from qualitative interviews, and do not account for deductive methods such as reviews or existing scale adaptation.[105] This is inconsistent with other sources, which suggest either approach is acceptable and a combination preferred.[81,160] Similarly, the cross-cultural equivalence framework adopted has been noted to be complex and difficult to adhere to in resource-limited settings.[161]

A drawback of the final thematic framework of scale content is that it contains too many domains to be practical for a single stigma scale (21 in total). Although not a concern for the quality of the review itself, this limits direct applicability of the framework in scale development. If adopted, the domains would need to be grouped or separated into different scales. These options are explored in Chapters 3 and 4.

2.5.6 Conclusions

Assessment of stigma using scales is a potentially useful aspect of outbreak response, offering a structured means of understanding how stigma manifests, changes over time, and influences health-seeking and social behaviours. This review shows that while numerous similar stigma scales have been developed for assessing outbreak-related stigma, their methodological quality, ability to inform response, and reuse is often limited. Addressing these gaps, particularly concerning content validity, cross-outbreak applicability, and psychometric rigour, would enhance the ability of future outbreak responses to monitor stigma more effectively.

3

International stakeholder interviews

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3.1 Chapter preface

3.1.1 Overview

This chapter describes the development of a conceptual model of outbreak-related stigma. The resulting Hourglass Stigma Model is based on thematic analysis of 37 in-depth interviews with international stakeholders. The chapter also collates stakeholder suggestions for stigma assessment and mitigation. These suggestions inform the design of stigma assessment tools and guidelines in later chapters.

3.1.2 Publication and contributions

This chapter contains content from the following publications:

- **Paterson A**, Jones B, Kabajaasi O, Cheyne A, Tulunay H, Hadson K, et al. An hourglass model for conceptualising stigma in infectious disease outbreaks. *Scientific Reports.* 2025.
- **Paterson A***, Kabajaasi O*, Adlard F, Hadson K, Cheyne A, Ssewankambo Y, et al. Ebola stigma and its impact on outbreak control: lessons from key informant interviews in central Uganda. *Tropical Medicine & International Health.* 2025. (*joint first authorship)

For the work presented in this chapter, I was responsible for study design, data collection, data management and analysis, designing the figures and drafting the manuscripts. Co-authors were involved in conceptualisation, identifying eligible stakeholders, and refining the final model. A graphic designer, Beatrice Bosch, assisted with formatting the final figures. A medical student, Francess Adlard, assisted with double-coding for an Ebola disease-specific sub-analysis of this work.

3.2 Introduction

3.2.1 Background

Published work on outbreak-related stigma has largely taken the form of opinion pieces. While these have played an important role in raising awareness about the issue, there has been comparatively little focus on developing theory or practice-oriented frameworks.

As highlighted in Chapter 2, a well-fitting conceptual model is important for ensuring the relevance and comprehensiveness of stigma assessment tools and stigma reduction guidance.[90,162] While generic models of health-related stigma can be helpful, their development processes are often either unclear or based exclusively on non-outbreak contexts.[14,25] Acute infectious disease outbreaks result in distinct stigma dynamics, which are not accounted for in these broader models (Box 3.1).

Box 3.1: Distinctive features of outbreak-related stigma

- *Episodic pattern*: stigma tends to emerge suddenly, rapidly intensify, gradually recede, and recur in future outbreaks.
- *Heightened emotions*: acute emotional responses (e.g., fear due to uncertainty and infection risk) affect behaviours.
- *Institutional dynamics*: implications of (and for) trust in responders, health services, and authorities are amplified.
- *Response–stigma interplay*: control measures impact stigma, while stigma can complicate outbreak control.

However, even with a clear conceptual model, stigma assessment tools may still take multiple forms. Understanding which features would optimise the usability and utility of stigma scales in real-world settings requires engagement with experts and end-users. The perspectives of those with experience and vested interest are also valuable for identifying strategies to reduce stigma. This is especially true for operational approaches, such as adapting patient follow-up procedures to reduce identifiability. These are not recognised as formal "interventions" and therefore often missing from the literature.

3.2.2 Objectives

The primary objective of this chapter was to develop a conceptual model of outbreak-related stigma (Objective 2 of the thesis).

The secondary objectives were to:
a) establish stigma tool design specifications to optimise usability and utility, and
b) identify practical opportunities for stigma reduction in outbreaks.

3.3 Methods

3.3.1 Study design and reporting standards

For this qualitative component of work, in-depth interviews were conducted with international stakeholders involved in outbreak response. Insights from the interview data were identified and organised using thematic analysis. The methods and findings are reported in accordance with the Consolidated Criteria for Reporting Qualitative Research checklist.[163]

3.3.2 Rationale for methods

International stakeholders were chosen as the sampling frame for this chapter as they offered perspectives on practical realities and operational needs across contexts. This aligned with the aim of developing cross-outbreak tools. One-on-one in-depth interviews were used, rather than focus groups or workshops, as these allowed for detailed and individualised discussion, including sensitive accounts of personal experiences. The format also made it possible to involve stakeholders across dispersed locations and with limited availability. Thematic analysis was applied as it enabled integration of novel insights and established theory. As alternative analytic approaches, grounded theory risked overlooking the theoretical foundations laid by previous scholars, and content analysis risked under-representing insights from smaller subgroups.

3.3.3 Sampling strategy

Maximum variation purposive sampling ensured inclusion of interviewees with experience across a range of settings, diseases, and response activities. Stakeholders with experience in (re)emerging infectious disease outbreaks were specifically sought from each of the following groups:

- executive and senior leads of health emergency response organisations (including WHO, Médecins Sans Frontières, International Federation of Red Cross and Red Crescent Societies (IFRC), and UNICEF)
- senior officials from national ministries of health
- leads/members of affected community organisations and lived experience groups
- risk communication and community engagement experts
- clinical and operational outbreak responders
- clinical and social science researchers
- health ethicists

All WHO regions and major recent outbreaks were represented in the sampling frame. After inclusion of at least one representative from all identified groups, sampling continued until thematic saturation, defined as the point at which no new subthemes emerged.

3.3.4 Recruitment

Potential interviewees were identified through institutional contacts and snowball sampling, with invitations to participate sent via email. Invitations included information on the purpose and nature of the research. No eligible stakeholders declined to be interviewed, however, interviews with two individuals could not be scheduled due to availability constraints.

3.3.5 Data collection

Once-off, in-depth interviews were conducted with 37 stakeholders between August 2023 and June 2024. The interviews were conducted one-on-one using Microsoft Teams and a pre-tested topic guide (Appendix B.1). Interviewees were in private spaces, either at their workplaces or at home.

I conducted all interviews myself, as a clinician-researcher with training in qualitative methods and experience in outbreak response independent of the contacted stakeholders. Professional interpretation services were made available, however, all interviews were conducted in English. While the interviews focused on (re)emerging infectious diseases, interviewees were also invited to draw on broader experiences related to established or endemic infectious diseases, such as HIV, tuberculosis, and leprosy, where relevant (see Box 3.2).

Box 3.2: A note on the use of the term 'leprosy'

As mentioned in Chapter 1, some scholars have proposed the term 'Hansen's disease' as an alternative to 'leprosy' in an effort to reduce the associated stigma.[32] However, eponyms are not ideal alternatives for disease names. In this case, the proposed name refers to G. H. A. Hansen, the physician who identified the infectious cause of leprosy but who was later found guilty of unethical human experimentation.[164] As a result, this name has been met with resistance in the academic community.[165] The term 'leprosy' is therefore retained in this thesis, although efforts to identify a less stigmatising disease name are supported.

Interview questions broadly focused on (1) interviewees' positionality and outbreak experience, (2) manifestations of stigma observed during or following relevant outbreaks, (3) factors that contributed to these manifestations, (4) the perceived impacts of stigma, and (5) suggestions for future stigma monitoring and reduction.

Interviews lasted 25–60 minutes and, with consent, were securely audio-recorded and transcribed verbatim. Transcripts were not returned to interviewees, however, each transcript was reviewed while re-listening to the original audio-recording to ensure accuracy. This process also enabled initial familiarisation with the data.

3.3.6 Data analysis

Interview data were analysed using a mix of inductive and deductive thematic analysis. Data analysis was performed alongside data collection (Figure 3.1). This facilitated exploration of emerging ideas in subsequent interviews. The research team met weekly to discuss interim findings.

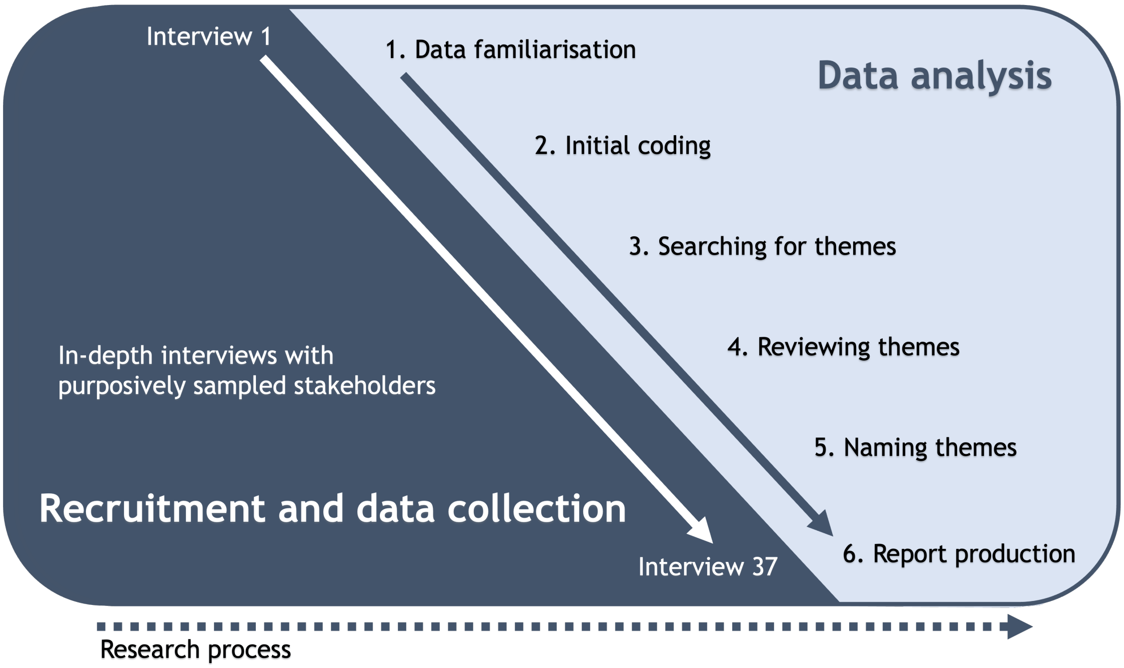

Figure 3.1: Overview of qualitative study methods. Thematic analysis phases based on Braun and Clarke[166]; depiction of concurrent data collection and analysis inspired by Pope and Mays[167] (used with permission).

Transcripts were uploaded to NVivo qualitative data analysis software (version 14).[168] Uploaded transcripts were then reread for further familiarisation, and independently coded using an iteratively adapted codebook (a sample of the transcripts were later double-coded for a sub-analysis).

For the primary objective, major themes were developed inductively by grouping relevant coded data, with subthemes derived using applicable social and behavioural theories. A UNICEF synthesis of 25 social and behavioural theories[169] and five widely recognised health stigma theories[14,15,25,170,171] were reviewed for applicability to the data, with selection based on explanatory power, fit, and simplicity. The theories applied within each major theme are detailed in Table 3.1. Following this, themes (i.e. model domains) and subthemes (i.e. factors) were assembled into an explanatory analytic model (early iteration provided in Appendix B.2).

Table 3.1: Socio-behavioural and stigma theories applied to create subthemes within each model domain

Relevant theories	Core ideas applied within each model domain
Context	
Socio-ecological model	Several concentric layers shape a person's behaviours.[172]
Social norms theories	Behaviour may be determined by how others behave (empirical expectations), and/or how others expect the individual to behave (normative expectations).[173,174]
Social network theory	Networks can influence individuals connected to others who engage in a particular behaviour, and who may persuade the individual to adopt a new behaviour.[175,176]
Media effects model	Agenda setting, priming, and framing by the media are powerful determinants of specific behaviours, often exploited for political, social, or economic gain.[177]
Jones stigma dimensions	Six features are commonly associated with stigma: concealability, course, disruptiveness, peril, origin, and aesthetics.[170]
Thoughts	
Health belief model	Self-efficacy and cognitive biases influence how a person perceives the severity of a threat and the benefits or costs of a given action.[178]
Decision-theoretic model of collective behaviour	Behaviours may be driven by personal beliefs alone (non-social) or shaped by social expectations (social/collective behaviour).[174]
Attribution theory	People make causal attributions based on perceptions of controllability and stability of an event.[179]
Emotions	
Evolutionary theory of cognitive biases	Cognitive "errors" such as stereotyping may persist because they were evolutionarily advantageous in forming rapid judgements.[180]
Manifestations	
Reasoned action and planned behaviour model	Personal beliefs shape attitudes, which then influence behavioural intentions.[181,182]
Jones and Corrigan stigma model	Stigma arises through a sequence: stereotypes (biased information), prejudice (negative beliefs and emotions), and discrimination (behavioural responses).[14]
Link and Phelan stigma theory	Stigma emerges through the co-occurrence of labelling, stereotyping, separation, status loss, and discrimination, within a context of power.[171]
Impact	
Complex systems theory	Cognitive, social, and structural influences on stigma are multicausal, multidimensional, and interdependent.[183]
Socio-ecological model	As described under Context domain.

Behavioural theories were selected from a UNICEF synthesis by Petit.[169]

Following model refinement, *key considerations* were identified that linked factors within and across domains and held significance for outbreak preparedness. Each consideration captures a recurring insight from stakeholders, with corresponding reflective questions collated in the discussion.

Three interviewees, with expertise across patient advocacy, clinical response, health policy, and social science research, reviewed the model and related findings to confirm they accurately represented the interview content.

For the secondary objectives, codes were initially grouped by: a) usefulness or usability (for the stigma tool specifications), and b) outbreak phase (for the stigma reduction suggestions). The rest of the analysis was inductive, with subthemes developed directly from the data.

3.3.7 Ethical considerations

This study was approved by the University of Oxford's Medical Sciences Division Research Ethics Committee (reference R87073/RE001). All stakeholders provided informed consent.

3.4 Results

3.4.1 Interviewee characteristics

The characteristics of the 37 stakeholders who participated in interviews are detailed in Table 3.2.

Table 3.2: Interviewee characteristics

Characteristic	**No. interviewees (%), N=37**
Roles in outbreak response*	
Clinical care	21 (57)
Response coordination and operations leadership	20 (54)
Social science research	11 (30)
Patient advocacy	8 (22)
Psychosocial support	8 (22)
Policymaking and governance	8 (22)
Clinical research	7 (19)
Risk communication and community engagement	7 (19)
Training and capacity-building	6 (16)
Health ethics	3 (8)
Dignified burial	2 (5)
Health economics	1 (3)
Disease-specific expertise/response experience*†	
Coronavirus disease 2019	31 (84)
Ebola disease	24 (65)
HIV	15 (41)
Mpox	7 (19)
Marburg virus disease	7 (19)
Cholera	6 (16)
Influenza A (H1N1, H7N9, H5N1)	5 (14)
Nipah virus disease	5 (14)
Zika virus disease	5 (14)
Tuberculosis	5 (14)
Severe acute respiratory syndrome	3 (8)
Sexually transmitted infections	3 (8)
Dengue fever	3 (8)
Middle East respiratory syndrome coronavirus	2 (5)
Lassa fever	2 (5)
Shigellosis	2 (5)
Measles	2 (5)
Plague	2 (5)
Meningococcal disease	2 (5)
Other§	6 (16)
Regional experience*	
Africa	24 (62)
Europe	10 (29)
Americas	6 (18)
Western Pacific	6 (18)
South-East Asia	5 (15)
Eastern Mediterranean	2 (6)

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Table 3.2 – continued from previous page

Characteristic	No. interviewees (%), N=37
Positionality in outbreak response	
Local responder (in-country)	15 (38)
International responder	9 (26)
Experience as both	13 (35)
Reported personal experience of relevant conditions*	
Coronavirus disease 2019	20 (59)
Influenza A	3 (9)
HIV	3 (9)
Ebola disease	2 (6)
Mpox	1 (3)
Zika virus disease	1 (3)

*Interviewees may fit more than one category. †Disease categories based on WHO health topic titles[184]; endemic disease experience is also captured where relevant. §Other disease expertise includes anthrax, hepatitis E, Rift Valley fever, pertussis, non-polio enteroviruses, malaria, and a range of additional neglected tropical diseases.

3.4.2 The Hourglass Stigma Model

The cross-outbreak stigma model developed from the interviews is conceptualised as an hourglass (Figure 3.2). The model comprises five major domains: context, thoughts, emotions, manifestations, and impact.

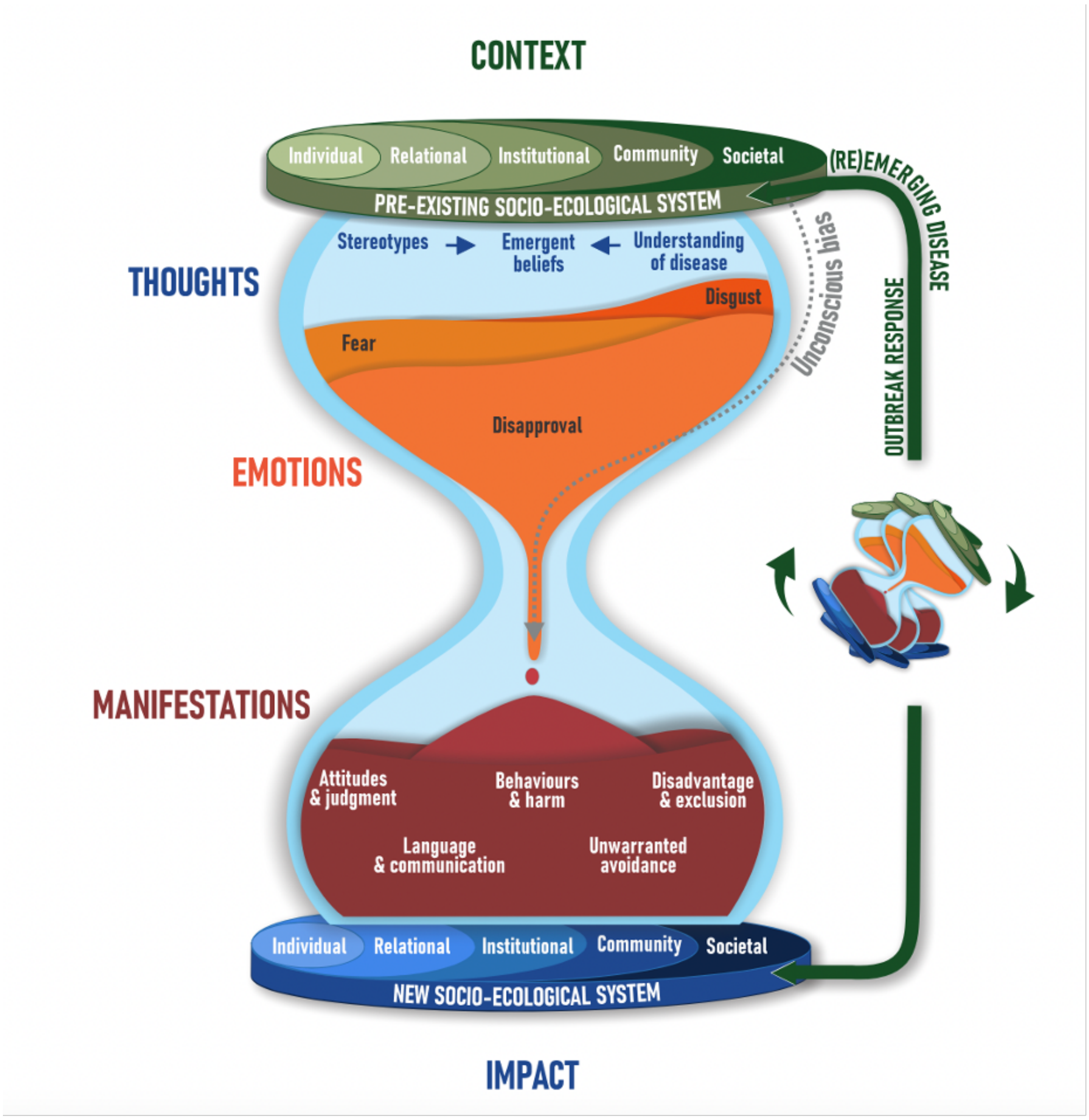

Figure 3.2: The Hourglass Stigma Model: a conceptual model illustrating the stigma process through five domains; figure published in Paterson et al.[185]

The hourglass structure was adopted to illustrate the broad array of contextual factors that contribute to stigma processes which, in turn, can lead to a wide range of effects. The model embodies the notion repeated by multiple stakeholders that ‘outbreaks begin and end in communities’. The socio-ecological systems mirrored at the top and bottom of the model underscore that the impact of stigma from one outbreak shapes the environment for future outbreaks. That is, in a subsequent outbreak, the hourglass will turn, and the emergent socio-ecological system becomes the ‘pre-existing context’ which drives or mediates stigma in the new outbreak. The principal findings within each domain of the Hourglass Stigma Model are presented below.

Domain I: Context

The model identifies three aspects of an outbreak context to be considered: the pre-existing socio-ecological system, the (re)emerging disease characteristics, and the outbreak response, all of which interact with one another. All contextual factors can be both drivers and mediators of stigma.

Pre-existing socio-ecological system

The factors for consideration within the pre-existing system are detailed in Figure 3.3 with illustrative quotes for each factor provided in Appendix B.3.

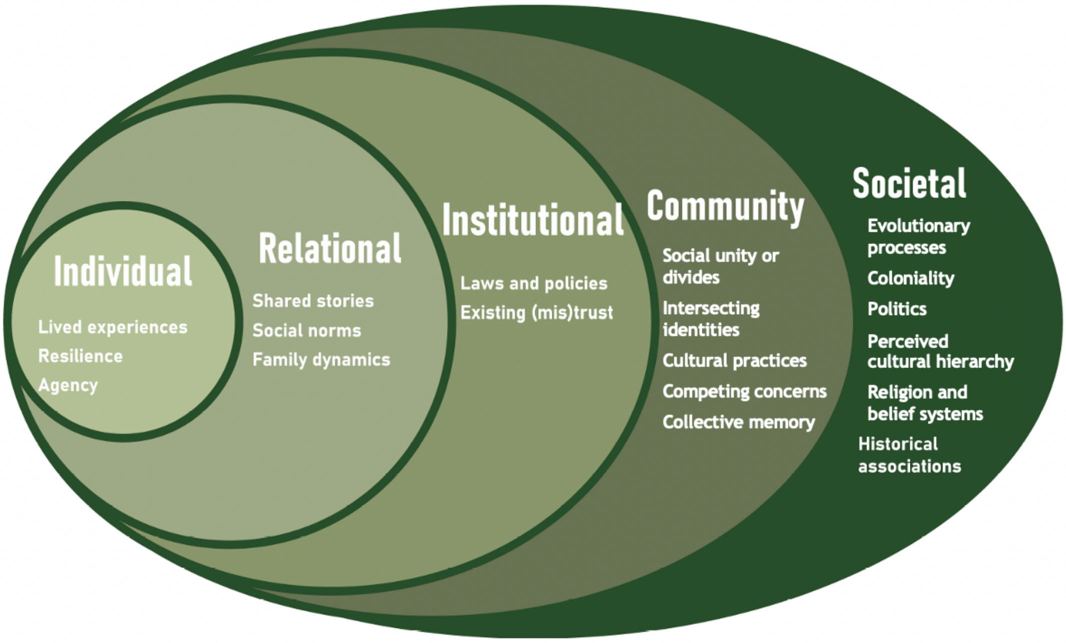

Figure 3.3: Factors within the pre-existing socio-ecological system. Levels are based on the socio-ecological model[172]; figure published in Paterson et al.[185]

A common stakeholder observation on the role of pre-existing systems was that **collective memory contributes to (re)emerging stigma (*key consideration***

***1*)**. This includes collective memory of colonial interventions.

> *"Each country, each community, has their way of thinking and living. But there's a history of eradication campaigns run by tropical medicine, you know, the monsoons of medical officers and massive colonial eradication campaigns. And I believe that there's something about that stigmatisation. And it is something about the power imbalance in the dynamics. I think that's still at stake nowadays in many countries."* – Interview 23, International response coordinator

The resulting mistrust was considered a catalyst for narratives that contributed to stigma.

> *"I remember there was a suspicion. The feeling was that the white people have brought Ebola here because they want something from us."* – Interview 14, COVID-19 and Ebola disease response trainer and psychosocial lead

Collective memory of recent outbreaks was also seen to affect perceptions of new outbreaks, even when due to different diseases. For instance, SARS-related stigma was believed to have shaped responses to COVID-19.

Another common reflection on the interaction between pre-existing systems and outbreaks was that **there is stigma associated with not keeping to cultural practices and social norms (*key consideration 2*)**. For instance, a stakeholder reflected on the differing norms and resulting social implications of mask use in the early phases of COVID-19.

> *"It's interesting because in Korea we have a kind of culture of wearing masks even before Covid. You can wear masks. People don't care about that. But in the US they don't have any culture like that. So they stigmatise people who wear masks."* – Interview 12, COVID-19 social scientist

In the case of Ebola disease, all stakeholders with experience of outbreak response raised safe and dignified burials, and the related restriction on cultural practices, as a potential driver of stigma.

> *"You've got a bunch of issues coming into conflict with cultural practices. And I think that promotes a new type of stigmatisation. If washing of the body or touching the body are something that's very much part of your culture, I think it's very hard to give that up, even as a health message."* – Interview 20, International governance and policy advisor

This was noted to further contribute to a sense of mistrust between affected communities and response teams, deepening unease and fostering rumours.

> *"In the beginning we were told strictly that there would not be any confirmation [of a death by relations]. The surveillance team would first go to that village and alert the people that a person has died and then we would organise and just go direct to the grave. And so that made people not feel comfortable because we were burying their people, but they have not confirmed the death."* – Interview 28, Ebola disease burial team member and COVID-19 infection control worker

Emerging context: disease and outbreak response factors

Disease characteristics and outbreak responses believed to affect the extent of stigmatisation are mapped in Figure 3.4.

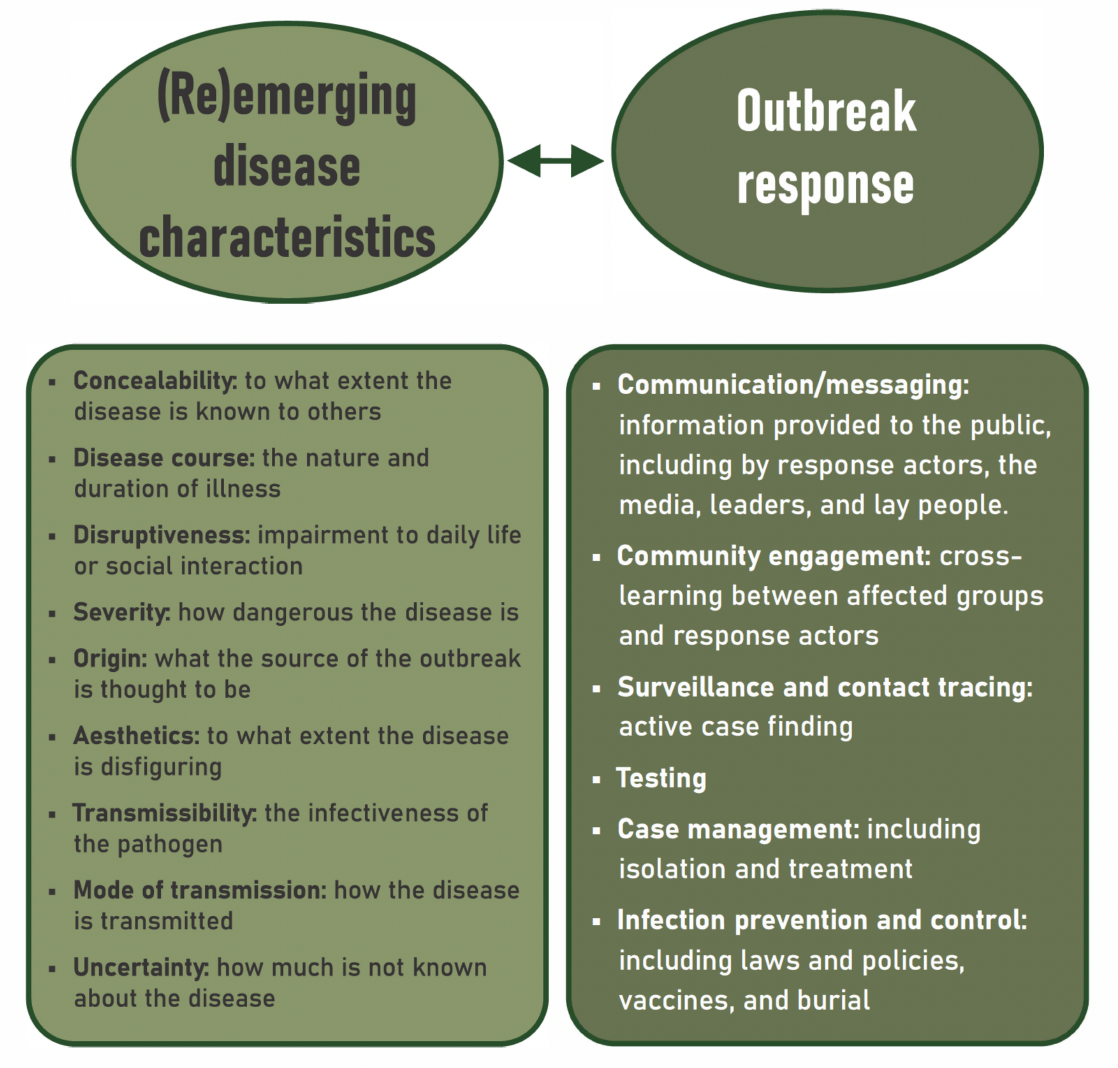

Figure 3.4: Disease and outbreak response factors that influence stigma. Categories are based on Jones' Stigma Dimensions[170] and GOARN Outbreak Response Pillars[53]; figure published in Paterson et al.[185]

Interviewees described how disease characteristics and outbreak response efforts not only affect the pre-existing socio-ecological system (as illustrated in the burial practices example) but also impact one another.

In particular, stakeholders commented on how **outbreak response measures can reduce disease concealability (*key consideration 3*)**. Various outbreak control measures (including surveillance, testing and notification, research involvement, and healthcare visits) were noted to make those who had the disease more identifiable, facilitating stigma.

> *"If it's a subtle disease that isn't obvious to people, then taking part in a trial and someone seeing that you're taking some medicines at home... you could identify yourself there."* – Interview 3, Multi-outbreak clinician-researcher

One stakeholder commented on how test results (particularly of notifiable conditions) can mark people even in the absence of physical signs of disease.

> *"Some of the outbreaks that occur really bring back the stigmatising behaviours both at the individual and collective level related to infectious disease that don't seem to have changed for thousands of years. Even if we now identify who is infected using a PCR test as opposed to a visual marker of disease. But I think it's remarkable how persistent that can be."* – Interview 5, Multi-outbreak health ethicist and policy advisor

Many reflected on how this prospect of reduced concealability made communities more hesitant to embrace outbreak response measures.

> *"In my experience in Vietnam, in SARS-1 and bird flu, when we went to the communities to do contact tracing, the patients and their families were very reluctant to see public health officials because it was very stigmatising, and the families were often shunned by the community, and they weren't involved in the communities. People weren't talking to them and they lost jobs."* – Interview 9, Multi-outbreak clinical research lead

This created a sense of trade-off between physical and social wellbeing, contributing to avoidance of diagnosis and medical care.

> *"I had people [with mpox symptoms] say to me "it's not possible for me to be quarantined" or "it's not possible for me to see someone, because if my parents knew about this and what I was being quarantined for... I'm not out to them. So I can't go," and in my head it makes sense that you can't go, even though as a public health person, I'd say please go, it sounds like it's a high chance that it could be mpox based on what you're saying. But from a very human level and a community level, I think it's ineffective for us to push things like that."* – Interview 32, Multi-outbreak public health practitioner and community advocate

As in the quote above, it was noted that concealability concerns extend beyond the disease itself to associated aspects of identity, such as sexual orientation.

Multiple stakeholders described how **religious, political, and historical associations can result in moralisation of particular modes of disease transmission (*key consideration 4*)**. This phenomenon was noted for diseases associated with drug-use:

> *"It was predominantly drug users who were involved with the anthrax outbreak in 2010. And of course, they're just often treated as though, you know, they're the lowest of the low."* – Interview 11, Multi-outbreak response coordinator

It was also prominent in relation to sexual transmission:

> *"From my experience the stigma comes to the play in a much bigger way when it's a sexually transmitted condition. So when it involves sex, it automatically comes with stigma around certain communities such as gay, bisexual, [men who have sex with men] communities. All because sex is still taboo itself."* – Interview 7, Community advocate with lived experience of mpox

Lastly, mode of transmission was noted to be associated with stigma in the case of specific intermediate hosts:

> *"With Nipah when I was a child, it was very much considered a pig disease. And there were lots of tensions at the time between people who ate pork and didn't because of religious reasons in Southeast Asia. This was also the time of major race riots. Quite a few people like me were being massacred in Indonesia around that time and tensions were therefore high. So I think the association of Nipah virus with pigs as an intermediate host was quite politically charged."* – Interview 10, Multi-outbreak clinician-researcher

Domain II: Thoughts

The Hourglass Model depicts how contextual factors come together to influence thoughts about the disease and those affected. Interviewees described how stereotypes (from the pre-existing context) and understanding of the disease (from the emerging context) inform these thoughts. These cognitive pathways, and common beliefs identified in the interviews (e.g. affected people are immoral, cursed, dirty), are summarised in Figure 3.5.

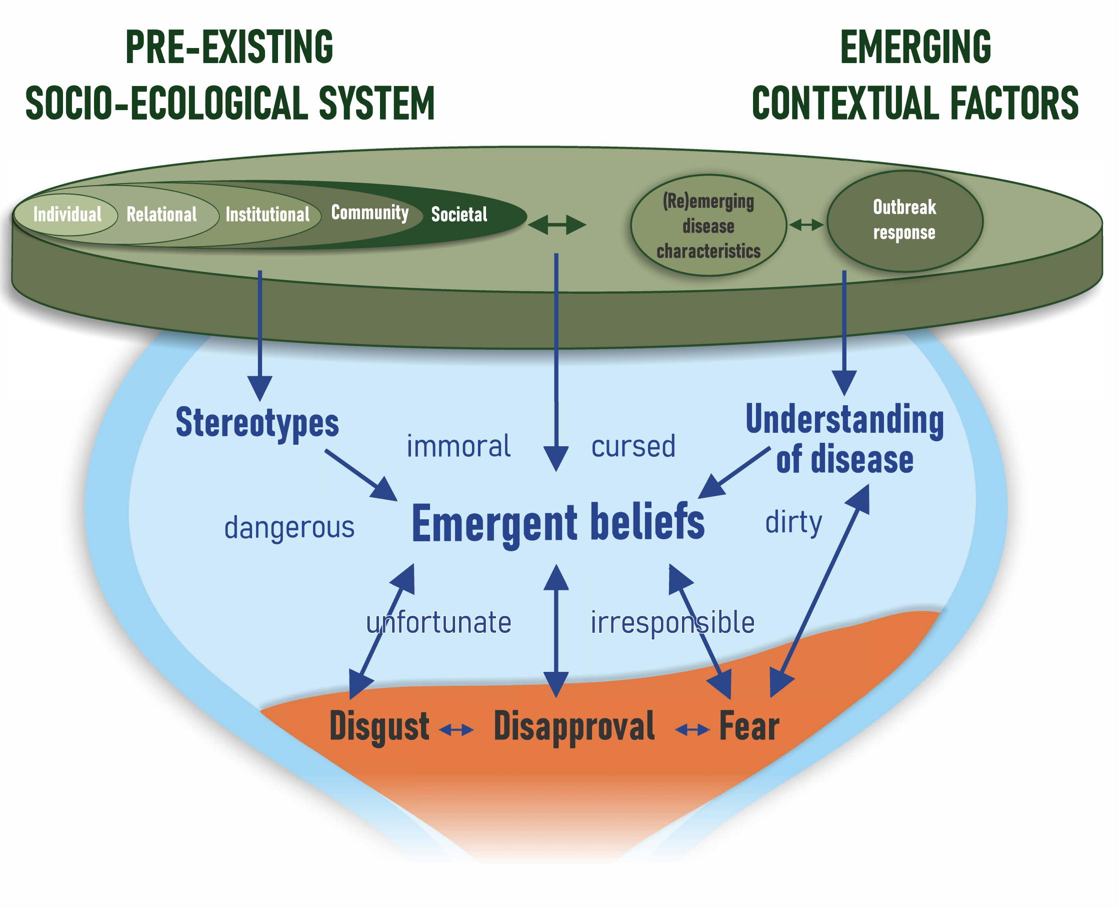

Figure 3.5: Cognitive aspects of the stigmatisation process in relation to context and emotions; figure published in Paterson et al.[185]

The stakeholders' shared concern that **those who cannot adhere to prevention measures may unjustly be marked as irresponsible** (***key consideration 5***) is an example of how pre-existing context (social divides) and outbreak response combine to form an emergent belief.

> *"You become ostracised or stigmatised because you cannot follow the policy. But the policy is not appropriate for you in your setting, right?"* – Interview 20, International governance and policy advisor

The stigma associated with the disease was therefore believed to be compounded by intersecting aspects of identity, such as gender, class, or geography. These intersections shaped individuals' ability to comply with public health guidance, but did not necessarily shield them from judgement when they could not.

> *"Zika was so hard because the communication was so poor and it was very much, well just don't get pregnant. Like that's even possible. And so stigma from not 'following instructions' from the Ministry of Health [meant that getting Zika] was "are you going to be a bad mother? Are you being selfish? Are you just ignorant?" The stigma was you're a fool or you're dirty, which... this idea of hygiene and dirt just goes across any level of stigma."* – Interview 4, Multi-outbreak behavioural scientist

As suggested by the last quote, another prominent concern was that **hygiene-dominant public health messages can result in beliefs that people who get the disease are 'dirty', exacerbating social divides (*key consideration 6*)**. This was particularly noted for specific diseases, such as cholera.

> *"In something like Ebola or Covid, there are, of course, social and economic factors, but everyone more or less can get these things. Whereas for cholera, if you're rich and have toilets and water, it's just not going to happen, or at least very unlikely. And so, you see much more of that piggybacking of saying, well, these people are dirty and therefore they get cholera. And people who have cholera are dirty people, and around and around you go."* – Interview 16, International outbreak response coordinator

The cognitive aspect of stigma most frequently commented on was the connection between knowledge and stigmatising beliefs. While a few stakeholders suggested that stigma primarily arises from a knowledge-deficit, most emphasised that **the relationship between knowledge of a disease and amount of stigma is not linear (*key consideration 7*)**. This non-linearity was attributed to multiple contextual mediators, which meant that disease knowledge was not the only factor affecting emergent beliefs.

> *"We still just assume that people are logical and rational creatures and that therefore means that they will make their decisions based on the best health information. And people can be hyper-rational, but religious information, social information, cultural information, power dynamics, all of these things are playing into their decision making... And I think stigma comes into that, in that we just assume, well, if I tell you more information about this disease, you will make the right choice."* – Interview 16, International outbreak response coordinator

Ongoing questioning, despite the availability of disease information, was offered as evidence of the limits of knowledge for reducing stigma.

> *"If you live within a certain cultural model, you have two questions you always ask, two 'Whys'. The 'Why empirical' is what we all use. I'm crossing the road, a car knocks me down, I break a leg. You know if the car didn't hit me, I wouldn't break my leg. That's clear enough for anybody to understand, right? And people do believe that. But then there's that back thinking, oh, why me? Why today? Why? Right? That's the 'Why two'... And I'm not saying that we should turn medical doctors into spiritualists, but at least we need to take that seriously. And not ignore it completely."* – Interview 21, Multi-outbreak health ethicist

Some interviewees drew the connection between the above consideration, concerning the limitations of knowledge for reducing stigma, and another: that **people may use a disease as a reason to further stigmatise groups they morally disagree with (referred to as moral-piggybacking[39]) (*key consideration 8*)**. An interviewee gave an example from the 2022 global mpox outbreak:

> *"The comments I saw on Twitter were in the context of mpox, but they're the kind of comments that you get that are actually driven by underlying homophobia rather than anything else. But of course, that is quite important when you've got one disease that is affecting a particular group and those people happen to be gay."* – Interview 3, Multi-outbreak clinician-researcher

Domain III: Emotions

The third domain of the Hourglass Model reflects the emergence of emotional responses to an outbreak. While these are often derived from cognitive processes, it was also noted that **emotional responses (such as fear) can be triggered by automatic negative reactions and therefore difficult to eliminate (*key consideration 9*)**.

> *"We get anxious and we get afraid because it's our way of making sure we stay out of danger. So it's hard to work out what the solution to that is."* – Interview 8, mpox non-governmental response coordinator and community advocate

> *"We are humans and once we identify anything that could threaten us, of course we try to distance ourselves from it."* – Interview 27, COVID-19 clinical responder and Ebola survivor programme lead

The similarities in the above comments suggest that this consideration holds true across contexts.

A shared concern among interviewees was that **using fear to increase adherence to preventive measures may have undesired consequences (*key consideration 10*)**. Stakeholders explained how fear appeals in outbreak communication may result in reduced rationality or compassion:

> *"I think the truth can be scary and we have to tell people the truth. But intentionally scaring people, I don't think it's ethical, and I also just don't think it gives results. If you're being purely machiavellian, I don't think it works because scared people do not make good decisions. People run the wrong way in fires. People make stupid decisions in disasters, fear does not make us more compassionate people and it does not make us more effective decision makers. We also know that fear wears off over time... so if [an outbreak response] is based on people being afraid of this threat, if the threat lasts longer than the adrenaline surge does, then we just become accustomed and we move on, even though the risk has not actually decreased."* – Interview 16, International outbreak response coordinator

Other stakeholders described how this fear drives false disease narratives and stigmatising conspiracy theories:

> *"To be rationally fearful is one thing. But most of our fears are not rational. This gives a good breeding ground for conspiracy theories, and myths, because it breaks down the trust system. And once people are under a form of repression they are more likely to buy into stories."* – Interview 21, Multi-outbreak health ethicist

Domain IV: Manifestations

When asked about how stigma was visible in their settings, stakeholders' varied responses demonstrated that **stigma extends beyond overt discrimination against individuals with the illness (*key consideration 11*)**. Figure 3.6 charts the range of stigma manifestations with examples provided in Table 3.3.

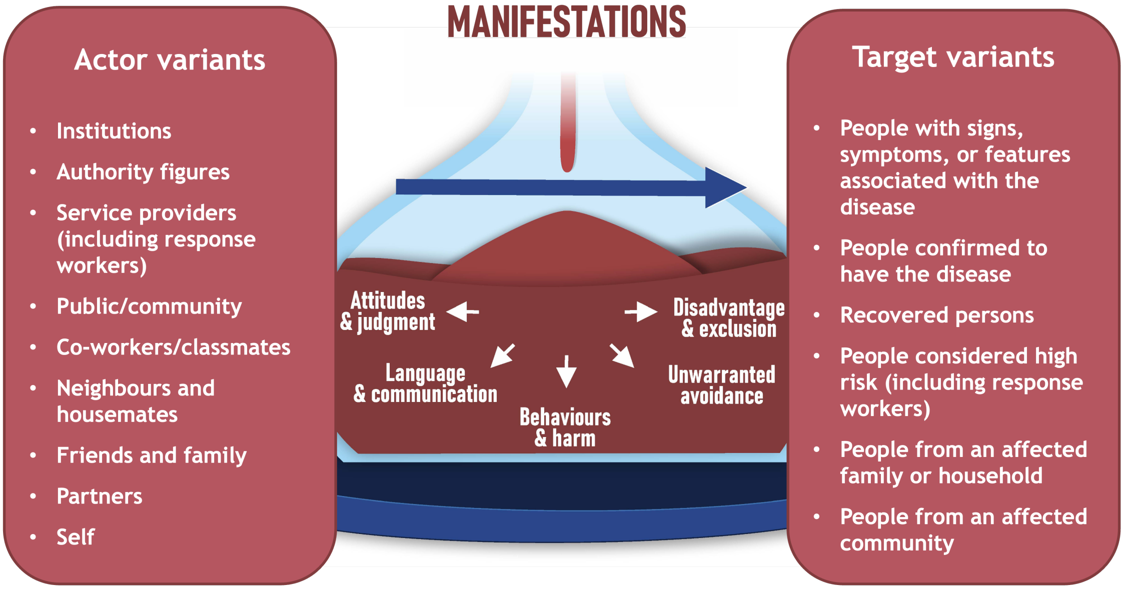

Figure 3.6: Stigma manifestations with actor and target variants. Actor variants refer to those enacting stigma, while target variants are the individuals or groups affected; adaptation of figure published in Paterson et al.[185]

Table 3.3: Examples of different stigma manifestations

Interviewee quote	Actor	Target	Disease
Attitudes and judgement			
"It's often households, I felt, that you're culpable as a family. Particularly so in bird flu, H5N1, anyway, a lot of children are affected and their families felt the impact of stigma." - Interview 9, Multi-outbreak clinical research lead	Community, institutions	Family, household	Avian influenza
Language and communication			
"I met some survivors from way back in Gulu outbreak. That was 2001. And one of them was telling us that he stood for some political positions and they were saying his opponents were referring to him as Ebola. This is a candidate for some position, but you're not even using their name. They're just saying, "oh, that Ebola candidate, that Ebola candidate"." - Interview 13, Medical doctor and Ebola survivor	Community	Recovered persons	Ebola disease

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Table 3.3 – continued from previous page

Interviewee quote	Actor	Target	Disease
Behaviours and harm			
"Again, there was geographic association... that it had come from China. So there were a lot of targeted racist attacks in London. So there was a young student from Singapore who was beat up for it. I had patients who refused to see me in the hospital. I had senior staff members say to me that it was probably better I dealt with the Covid patients because, you know, subtext, people think that you might have caused it sort of thing. So that was... that was quite tough." - Interview 10, Multi-outbreak clinician-researcher	Public, co-workers	Persons with associated features	COVID-19
"My first work with cholera outbreaks, um, I remember cars being stoned. No access to certain villages because we were 'bringing the disease in'... And we always feared when going to a cholera outbreak that without good sensitisation to the community, we were going to pay the price." - Interview 24, Former senior lead of international outbreak response organisation	Community	Response workers	Cholera
"One of our colleagues was investigating the virus, investigating Nipah. And they actually locked her in a house in a village. And then we needed to go with police and other local administrator to get her back." - Interview 31, Nipah, avian influenza, and COVID-19 clinician-researcher	Community	Response workers	Nipah virus disease
Unwarranted avoidance			
"I think I just got ashamed when I was out of the [Ebola Treatment Unit] and I was home. I spent two weeks at home. I would never come out of my house because I was fearing being out for the public to see me. I was ashamed of Ebola. I felt like, how will people take it?" - Interview 30, Ebola survivor and peer support lead	Self, community	Recovered persons	Ebola disease
"I remember a story from a man in Indonesia who was saying he had been treated and he was no longer contagious, but nobody would be willing to pray next to him at the mosque. So he rather decided that he didn't want to go anymore. And so you get this kind of internalised stigma kicking in, which basically means that the net effect on people's social functioning can be quite similar as when they are ostracised." - Interview 6, Infectious disease stigma researcher	Community, Self	Recovered persons	Leprosy
Disadvantage and exclusion			
"But for the survivors, of course, it was a cost because landlords were chasing people from their houses." - Interview 25, COVID-19 and Ebola disease psychosocial team member	Providers (landlords)	Recovered persons	Ebola disease

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Table 3.3 – continued from previous page

Interviewee quote	Actor	Target	Disease
“When we were asking for money to support people there was this rhetoric of, "Oh, we need to be careful what we do with taxpayers money". And the point that was made time and time again was that gay, bisexual men are paying tax as well. They are. They’re not this separate entity outside of the rest of the population. They’re also funding the [National Health Service]. So when they need it, they should be able to benefit from it.” - Interview 8, mpox non-governmental response coordinator and community advocate	Institutions	Affected communities	mpox
“And of course there are some things, like you’re exporting goods... and some people would shy away from them. Well, this is coming from a district that has Ebola, the district that is on a lockdown. So I don’t think I want to take this.” - Interview 13, Medical doctor and Ebola survivor	Public, institutions	Associated communities	Ebola disease

Interviewee quotes illustrate the different manifestations of stigma across a range of infectious disease outbreaks. The ‘Actor’ column indicates who enacted the stigma, while the ‘Target’ column specifies the group affected.
COVID-19 = Coronavirus disease 2019

These manifestations of stigma are thought to mostly arise from the cognitive and emotional pathways described. However, **stigma may also be enacted directly from contextual factors, without negative beliefs or emotions, due to unconscious bias (*key consideration 12*)**. This is illustrated by the dotted line in Figure 3.2. Stakeholders discussed the use of terms such as ‘Chinese virus’ in COVID-19 and recurrent use of war analogies as examples of how people may unknowingly propagate stigma.

> *“The polarised representation is sort of good versus evil. It’s the good people fighting the evil virus. And that kind of polarisation then tends to put you in one camp or the other. You know, almost any epidemic or outbreak is ‘it’s a war’ but personally I’m not sure it’s the right messaging actually. I think it’s probably unhelpful in general. And it might be better framed as a community activity against a natural disaster rather than a fight against an evil pathogen.”* – Interview 9, Multi-outbreak clinical research lead

Domain V: Impacts

The final model domain is concerned with the impacts of stigma. Impacts described by stakeholders could be mapped back to all socio-ecological levels (Figure 3.7). This creates a *new* socio-ecological system which changes the profile of stigma in future outbreaks, reflecting the turning of the hourglass.

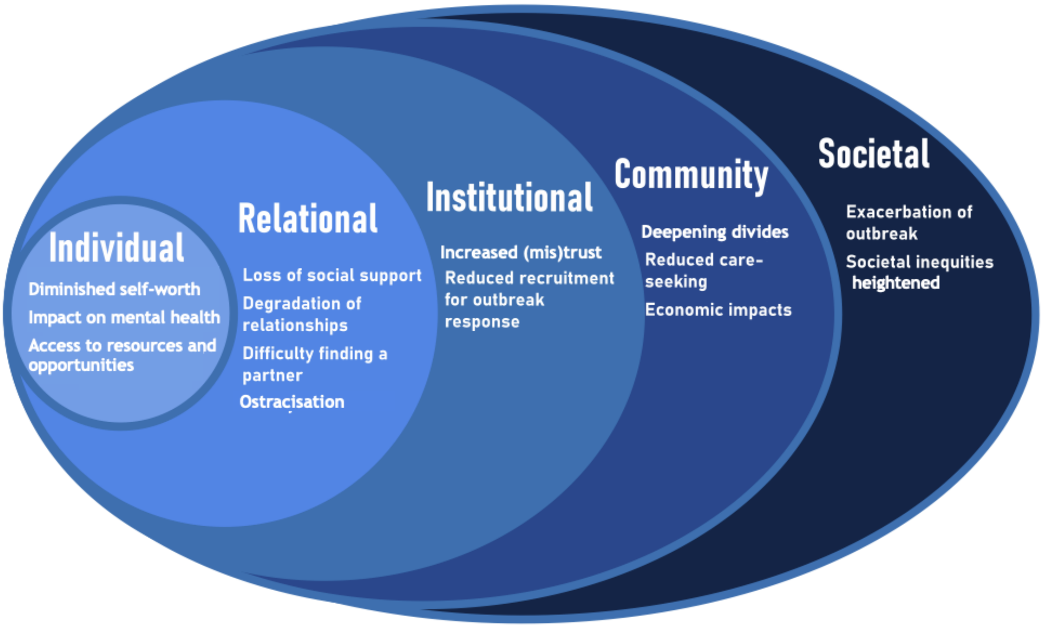

Figure 3.7: Impacts of stigma resulting in the emerging socio-ecological system. Levels are based on the socio-ecological model[172]; figure published in Paterson et al.[185]

On an individual and relational level, it was evident from the interviews that **stigma has psychosocial consequences that outlast the disease (*key consideration 13*)**.

> *"In our settings, in Africa, and Uganda in particular, we've not really embraced mental health. And it is something that is really important and we need to try to embrace it because a person who has recovered from Ebola himself or herself has to be mentally prepared, mentally know that "I am okay. I have recovered. I'm totally fine. I can go back to normal function"."* – Interview 13, Medical doctor and Ebola survivor

At an institutional level, comments returned to *key consideration 1* on collective memory, noting that **stigma manifestations can have a lasting impact on**

trust in institutions (*key consideration 14*). It was emphasised that the solution to this issue is not finding ways to increase community trust but rather improving the trustworthiness of response actors. In line with this, one stakeholder termed community members' scepticism 'healthy mistrust'.

It was noted that the level of (mis)trust often varies over the course of an outbreak, and can improve over time, facilitated by effective treatments and established trustworthiness.

> *"Initially [concerns about stigma] made people not want to give away their loved ones, not report them to the healthcare workers. They would prefer to run with them to the traditional health worker. They'd prefer to hide them in the houses and treat them from their self-medication. But, again, this came with negative effects to the same families... And eventually they started opening up to the healthcare workers and this became more acceptable within the community. And actually, we began to see big numbers of survivors coming back to their communities. Then people started looking at the isolation facilities as the only areas where they could survive, something good."* – Interview 15, Viral haemorrhagic fever clinical trainer and responder

In terms of public health implications, stakeholders provided varied examples of how **stigma may worsen outbreak control (*key consideration 15*)**. A consistent concern was the impact stigma had on timely care-seeking, impeding the ability to rapidly contain outbreaks.

> *"I had two friends. I was with them and the patient [who had Ebola]. One was the first person to show up the signs. But he never turned up to go to the hospital. We buried this friend of ours who had died of Ebola on Tuesday, he turned up on Wednesday at my facility and was expressing the signs. I, myself, I told him to turn up and go to the hospital, to the regional referral. He refused. He said "I cannot go there. How will the community hear that I'm having that disease?""* – Interview 30, Ebola survivor and peer support lead

Some stakeholders noted that alongside reducing care-seeking, stigma also made people less likely to adhere to preventive measures such as mask-wearing, quarantine, or physical distancing, due to concerns that this would infer that they have the disease. This was seen to further hinder outbreak control.

> *"So many of those who had [COVID-19] symptoms, they'd actually go to the market, go to the common place. And that's why. They were hiding from testing so people couldn't tell that they've got this disease."* – Interview 31, Nipah, avian influenza, and COVID-19 clinician-researcher

In addition, stigma was believed to make recruitment of response personnel more difficult. This related back to perceptions of hygiene and dirtiness:

> *"For example, when I said to my family, I want to be an infectious disease doctor, I think their first reaction was, "but that's dirty work"."* – Interview 10, Multi-outbreak clinician-researcher

It was also due to the impact of association with the disease on social rapport, particularly for health workers from the affected community.

> *"Healthcare workers that were involved across the different response pillars, [infection prevention and control] in my case, there was a reluctance on the part of the community to engage with them, to freely socialise with them, and that in a way, I think, disillusioned people from being part of the responders. I have some cases where people felt, well, it's not worth it to really be a responder."* – Interview 14, COVID-19 and Ebola disease response trainer and psychosocial lead

As suggested by the quote above, this hesitancy was apparent across response activities. An interviewee involved in safe burials expressed that their teams were similarly limited by the lack of willing personnel. However, this reluctance was noted to not only be due to fear of stigma, but also fear of the disease itself.

3.4.3 Assessment tool design specifications

Following broader reflections on outbreak-related stigma, interviews turned to the practicalities of designing stigma assessment tools. Interviewees had mixed responses to the concept of quantitative stigma assessment. Many emphasised the need for increased monitoring or consideration of stigma in outbreak response, and were enthusiastic about the development and integration of stigma assessment tools.

> *"We certainly need, actually we needed this yesterday."* – Interview 22, Ministry of Health official

A range of intended uses for such a tool were proposed (Table 3.4).

Table 3.4: Anticipated uses for stigma assessment tool

Anticipated uses for tool with illustrative quotes
Raising awareness and advocacy
"I think it could be used as a way of highlighting the need for intervention." - Interview 10, Multi-outbreak clinician-researcher
Informing intervention design
"I think sometimes people look at the underlying causes for stigma and feel put off trying anything just because it feels sort of like a really large, complex problem that sometimes feels insurmountably big. So I think measuring it is a step in trying to persuade people. But I wonder how the measurement can guide people to doing something as well." - Interview 18, COVID-19 and TB stigma researcher and policy advisor
Evaluating interventions
"We do not have the tools to measure some of these [interventional] aspects. So we cannot objectively tell. We can only anecdotally say, well, this improvement is coming." - Interview 14, COVID-19 and Ebola disease response trainer and psychosocial lead
Anticipating impact on control measures over time
"One, it's got to give you a benchmark of how much stigma there is and how much it's likely to affect your control measures. So you need some sort of benchmark of severity of stigma which will inevitably change over time." - Interview 9, Multi-outbreak clinical research lead
Meeting funder requirements
"Generally speaking, funders are not very willing to give money for something that is not measurable where they can't actually see that what you're proposing is making a difference. So, for funders, it's very important that you do have measures that can measure the difference that your proposed interventions are going to make." - Interview 6, Infectious disease stigma researcher

However, some interviewees expressed hesitancy about the ability to adequately assess a phenomenon as complex and personal as stigma through quantitative means, particularly in new contexts.

> *"One thing around stigma that we do know is that it's sometimes very subjective and based on one's lived experiences. So how do we harmonise these two concepts: that it's something that is subjective, but we try and measure it in a very objective manner... I don't think it's impossible. But I think when it comes to a new pandemic or outbreak or disease X, there needs to be a very dynamic framework through which we construct a scale."* – Interview 32, Multi-outbreak public health practitioner and community advocate

Interviewees with both enthusiastic and more cautious views of quantitative stigma assessment had suggestions on how to optimise the usefulness of such a tool (Table 3.5, illustrative quotes in Appendix B.4).

Table 3.5: Stakeholder suggestions to enhance stigma assessment tool usability and utility

	Suggestions to optimise tool usability	Suggestions to optimise tool utility
Development suggestions	**Content:** • Favour items that are likely to still be relevant in future outbreaks **Item phrasing:** • Consider the sensitivity of questions for respondents who have experienced stigma • Use simple language **Tool length:** • Ensure short enough to be combined with other tools • Keep sufficiently brief to avoid respondent fatigue • Duration suggestions ranging from 10 minutes to 1 hour **Other considerations:** • Consider combining with qualitative interviews (although highlighted by others that conducting qualitative interviews requires substantially more training)	**Content:** • Include questions about employment • Include enduring aspects of stigma • Differentiate between preventive measures and stigma • Consider positive or neutral responses to illness too **Item phrasing:** • Account for challenges with getting honest responses/social desirability bias • Consider phrasing items to focus on social norms **Tool length:** • Ensure the results provide enough detail to meaningfully inform development of interventions • Ensure detailed enough to detect subtle changes over time **Other considerations:** • Explore having additional disease- or context-specific questions or modules
Validation suggestions	**Sampling frame:** • Consider non-response bias **Administration:** • Avoid paper or tablet self-administered surveys in settings where there is concern about disease transmission through indirect contact • Provide adequate guidance and support for future use and adaptation • Consider mixed interviewer- and self-administration depending on respondent literacy and preference **Methods:** • Allow for iterative refinement and changes to tool throughout testing	**Sampling frame:** • Position at the community level (while still including self stigma questions) **Administration:** • Consider emotional toll on interviewers • Minimise amount of data collector training required **Methods:** • Ensure robust psychometric validation with directly affected community members

3.4.4 Opportunities for stigma reduction

The final objective of the interviews was focused on stigma reduction. The following four overarching themes were identified in stakeholders' suggestions, relevant across outbreak preparedness, response, and recovery:

1. **Knowledge exchange:** improving public health communication and community engagement about the outbreak and socially sensitive ways to respond.
2. **Policy and service design:** structural or operational adaptations, such as changes to infrastructure or procedures that may be contributing to stigma.
3. **Psychosocial support:** psychological counselling, social support services, or skill-building resources to help with community reintegration and prevent or address the internalisation of stigma.
4. **Community involvement and advocacy:** decision-making and activism by and with people with lived experience of the illness and affected community organisations to ensure approaches take stigma into account.

Of these, suggestions addressing policy and service design were most common. These included measures such as ensuring that personal protective equipment use was proportionate to infection risk.

> *"The classic picture of people wandering around in spacesuits and knocking on people's doors and dragging out dead bodies - that really doesn't help with the stigma - or announcing names on speaker systems or putting up crosses on people's doors with quarantine tape and all that kind of stuff. It just heightens the anxiety around the disease. It heightens the perception that it's a dangerous disease associated with a household or a family. So all of those measures, I think they probably generally overdone."* – Interview 9, Multi-outbreak clinical research lead

Stakeholder suggestions are organised by outbreak phase and theme in Table 3.6 (with further illustrative quotes in Appendix B.5).

Table 3.6: Stakeholder suggestions for reducing stigma across outbreak phases

Preparedness	Response	Recovery
Knowledge exchange		
• Avoid disease names linked to places or animals • Provide anti-stigma training to outbreak responders • Train spokespeople to avoid criminalising, moralistic, or othering language • Integrate stigma education into schools and community dialogues	• Avoid fear-based messages • Promote two-way risk communication • Embed anti-stigma messages in risk communication • Address emerging local rumours • Centre messaging on transmission not identity • Highlight solidarity, not differences	• Provide recovery information for employers/educators • Avoid language that implies pity or defect when talking about recovery
Policy and service design		
• Design facilities to optimise safe contact with loved ones and healthcare workers • Build protocols that prioritise dignified, holistic care • Involve social scientists in guideline review • Improve trustworthiness of organisations	• Treat personal items respectfully and allow for retention when possible • Protect privacy during care provision • Involve local leaders before law enforcement • Allow visual confirmation after death • Consider temperature screening as reassurance • Consider if home-based quarantine possible • Ensure judicious use of protective equipment	• Reduce visibility of follow-up services • Facilitate visible respectful contact between outbreak responders and recovered individuals
Psychosocial support		
• Pre-plan psychosocial support programmes • Train and supervise psychosocial care providers adequately	• Involve support teams early • Support responder mental health • Strengthen factors that foster social cohesion • Provide resources at discharge if needed	• Ask about psychosocial wellbeing at follow-up • Facilitate recovery celebrations
Community involvement and advocacy		
• Involve local responders in planning and response to ensure sensitivity to community concerns • Engage potentially affected community representatives in outbreak preparedness • Engage with previously affected communities to avoid repeating mistakes	• Involve recovered individuals in community outreach roles • Co-design response measures and messages with communities • Ensure risk communication is locally led • Consult communities before rolling out new policies • Centre lived experiences in media	• Support peer-led recovery/survivor groups • Involve recovered individuals in community reintegration programmes

3.5 Discussion

3.5.1 Implications of the Hourglass Model for future outbreak response

Stakeholder accounts underscore that stigma is a recurrent feature of outbreaks, with tangible operational and psychosocial costs. By integrating established socio-behavioural theory and stakeholder insights, the resulting Hourglass Model is designed as a bridge between theory and practice in the field. To my knowledge, this represents the first conceptual model of outbreak-related stigma.

A consequence of the current gap between outbreak stigma reduction interventions and underlying theory is the indiscriminate reliance on default interventions, such as addressing any form of stigma with an education campaign, irrespective of what the root cause of the stigma may be. This raises concerns about the judicious allocation of scarce resources and the effectiveness of stigma reduction programmes. It also overlooks the possibility that outbreak response efforts may play a role in generating stigma. In these cases, it may be more effective to adapt response efforts rather than independently trying to address the resultant stigma.

Stigma is often regarded as a secondary social by-product rather than a central factor in public health decision-making. The Hourglass Model's 'Impact' domain challenges this tendency, highlighting that stigma can directly influence outbreak trajectories and public trust. Without structured methods for embedding stigma considerations into response strategies, control measures risk being ineffective or counterproductive.

The key considerations outlined in the results are intended to support reflection on stigma and how outbreak responses can perpetuate or prevent it. Too often, such reflection happens retrospectively or late in the course of an outbreak. Table 3.7

provides an example of how the model can be used in practice with a list of questions to prompt structured consideration of stigma from the start of an outbreak.

Table 3.7: Key considerations and prompts for outbreak responders, aligned with Hourglass Model domains

Key considerations	Reflective question prompts for outbreak responders
Context	
1) Collective memory contributes to (re)emerging stigma	Which previous outbreaks or events may affect how the community perceive this outbreak?
2) There is stigma associated with not keeping to cultural practices and social norms	What cultural practices and social norms may be disrupted by outbreak containment efforts? Is there a way to minimise this disruption?
3) Outbreak response measures can reduce disease concealability	Can outbreak response measures be adjusted to improve confidentiality while still reducing the spread of the disease?
4) Religious, political, and historical associations can result in moralisation of particular modes of disease transmission	Have the social practices associated with the mode of transmission previously had moral judgement associated with them?
Thoughts	
5) Those who cannot adhere to prevention measures may unjustly be marked as irresponsible	Are policies appropriate for all socio-economic levels of society?
6) Hygiene-dominant public health messages can result in beliefs that people who get the disease are ‘dirty’, exacerbating social divides	What contextual factors may be contributing to emergent beliefs? Is community listening occurring alongside education?
7) The relationship between knowledge of a disease and amount of stigma is not linear	What information sources are trusted by the community? Is a lack of accurate information contributing to stigma?
8) People may use a disease as a reason to further stigmatise groups they morally disagree with (moral-piggybacking)	Are disease prevention messages appropriate for all socio-economic levels of society? Are any communities/groups likely to experience compound stigma due to the risk communication messages? Can the messaging be redesigned to reduce this stigma? What can be done to support these groups?
Emotions	
9) Emotional responses (such as fear) can be triggered by automatic negative reactions and therefore difficult to eliminate	Is the fear associated with the disease proportionate to risk? Does the disease trigger a ‘disgust’ response? How can this be reframed in messaging?
10) Using fear to increase adherence to preventive measures may have undesired consequences	Is public health messaging purposefully appealing to fear? Could this impair rationality or foster misinformation? What actionable steps can be recommended alongside messages that may induce fear?

Table 3.7 – continued from previous page

Key considerations	**Reflective question prompts for outbreak responders**
Manifestations	
11) Stigma extends beyond overt discrimination against individuals with the illness	Which groups may be stigmatised due to association with the outbreak? Are families, healthcare workers, and specific communities at risk of stigmatisation too? How does stigma typically manifest in the affected community?
12) Stigma may be enacted directly from contextual factors, without negative beliefs or emotions, due to unconscious bias and social norms	What measures can be introduced to minimise exclusion of recovered persons? How might unconscious bias, including language choice, be contributing to stigma?
Impact	
13) Self stigma may have psychosocial consequences that outlast the disease	Are psychosocial support mechanisms available? Do they directly account for and aim to address stigma for all affected groups (including family members and response workers)?
14) Stigma manifestations can have a lasting impact on trust in institutions	How could the trustworthiness of institutions be enhanced, demonstrated, and maintained?
15) Stigma may worsen outbreak control	Is stigma likely to be reducing healthcare-seeking behaviour? Who are the alternative informal carers in the setting and how can they be better equipped?

The Hourglass Stigma Model complements and builds on the broader Health Stigma and Discrimination Framework,[25] but differs in several key respects. Firstly, while the latter considers contextual factors exclusively as drivers or facilitators of stigma, the Hourglass Model suggests that contextual factors may also be protective against stigma. For example, a context of community norms that are accepting of difference can minimise stigma in an outbreak. Secondly, the Hourglass Model situates institutions within communities in the socio-ecological system, rather than external to them. This emphasises that these institutions fundamentally operate within complex community structures alongside other actors. Finally, the Hourglass Model differs in that it offers an explanation of how factors might interact with one another.

3.5.2 Implications for future tool design

Interviewees identified multiple potential applications for a cross-outbreak stigma assessment tool, including advocacy, informing intervention design, and monitoring and evaluation. While most interviewees expressed enthusiasm for the idea, they also highlighted the importance (and difficulty) of ensuring such a tool is useful in practice.

Stakeholders cautioned that social desirability and non-response bias can distort findings. The need to overcome these limitations was highlighted in a recent stigma research prioritisation study.[161] Stakeholder suggestions to frame items at the community level and focus on perceived social norms could reduce these risks, and make questions less distressing for respondents.

A few stakeholders also noted that fixed questions may not capture all relevant nuances of stigma across contexts. Adaptations, additional items, qualitative components, or separate studies were proposed to address condition- or culture-specific aspects in greater depth. This was similarly flagged in the research prioritisation study.[161] Despite this, the authors maintained that generic stigma scale development is a priority,[161] as did most stakeholders.

A further tension was the length and comprehensiveness of the tool. Stakeholder suggestions reflected a desire for tools that were concise enough for operational use, yet detailed enough to support intervention design and detect gradual change.

These suggestions helped inform decisions on wording and structure during the stigma scale development process described in Chapter 4.

3.5.3 Implications for reducing stigma

Stakeholders proposed a spectrum of approaches to reduce stigma in outbreak contexts. The suggestions spanned knowledge exchange, policy and service design, psychosocial support, and community involvement.

A common thread was recognition that, although instinctive reactions to illness may be difficult to erase (as highlighted in *key consideration 9*), further information, humanising narratives, and positive interactions can moderate the influence of these reactions on ongoing behaviour. One way of understanding this is through what social psychologists have termed ‘two-factor theory’.[186] This theory describes how an automatic reaction, such as fear, is typically followed by a slower, more reflective process that integrates additional information. This can temper the initial response.

Clear communication, involvement of recovered individuals in community engagement, and visible demonstration of recovery were proposed as measures to support this shift from instinctive to considered responses. Conversely, strategies relying on fear appeals were considered disruptive to reflective processing.

These suggestions contributed to the formulation of the stigma reduction guidelines in Chapter 5.

3.5.4 Strengths and limitations

The strengths of this work include (1) the inclusion of participants from a wide range of professional and lived experience backgrounds, (2) the interview schedule, which balanced probing conceptual issues with eliciting practical suggestions, and (3) the iterative approach to thematic analysis, which allowed the model to be tested and refined in subsequent interviews, strengthening the final design.

However, the findings should be interpreted in light of several limitations. Network-based recruitment weighted the sample towards clinically-oriented stakeholders embedded in formal response structures. There was also greater representation of certain diseases and settings (e.g. COVID-19, Ebola disease, African Region) due to the frequency and extent of these outbreaks, and the contacts available through institutional networks. The requirement for internet access and time constraints may have further excluded community-based actors and active responders.

There were also language-related limitations. Most existing contacts were English-speaking and the invitation and information sheet were in English. Although professional interpretation was offered, interpreter-mediated interviews can be challenging, and some interviewees may have declined an interpreter, yet still found it more difficult to express themselves. Finally, there was no second coder for the primary analysis. Despite regular team debriefs and interviewee review, the absence of formal inter-coder checking introduces greater risk of interpretive bias.

The resulting Hourglass Model also has limitations. It is recognised that the model is unable to capture all the intricacies of a social phenomenon as complex as stigma. In addition, certain factors included in the model (e.g. emotions such as disgust) may not be relevant in all outbreaks.

3.5.5 Conclusions

This chapter brings together stakeholder observations of outbreak-related stigma dynamics. The resulting Hourglass Model provides a systematic approach for considering stigma in infectious disease outbreaks, with potential applications in response planning, health policy, and research. This model, together with practical suggestions from interviewees, provides the foundation for the next two chapters.

4

Development and validation of cross-outbreak stigma assessment tools

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4.1 Chapter preface

4.1.1 Overview

This chapter describes the development and validation of tools to assess outbreak-related stigma. Building on findings from earlier chapters, this process involved an expert Delphi, cognitive interviews, and survey administration in communities affected by mpox in the UK, Ebola disease in Uganda, and Nipah virus disease in Bangladesh, followed by psychometric analysis.

The chapter introduces a set of brief cross-outbreak validated scales, referred to as the (Re)-emerging And ePidemic Infectious Diseases (RAPID) Stigma Scales, as well as a detailed modular mapping tool, the Stigma Survey and Community-based Assessment for New and Re-emerging Outbreaks (Stigma-SCANR). It also provides two examples of how the Stigma-SCANR can inform stigma reduction efforts.

4.1.2 Publication and contributions

This chapter contains content from the following publications:

- **Paterson A**, Mughogho KM, Cheyne A, Kabajaasi O, Sarkar T, Dimitrios KH, et al. The (Re)-emerging And ePidemic Infectious Diseases (RAPID) Stigma Scales: a cross-outbreak scale development and psychometric validation study. *The Lancet Infectious Diseases.* 2025.
- **Paterson A**, Cheyne A, Tulunay H, Orkin C, Nutland W, Dunning J, et al. Mpox stigma in the UK and implications for future outbreak control: a

cross-sectional mixed methods study. *BMC Medicine.* 2025.

I took primary responsibility for this work, from establishing contract agreements to drafting the manuscripts. The research was conducted in collaboration with the research organisations Walimu in Uganda and icddr,b in Bangladesh. In Uganda, I trained and supervised the data collection teams in person with the local project lead (Olive Kabajaasi) and co-investigator (Dr Kkunsa Hadson). In Bangladesh, I provided online training and support to the data collection team with the local lead (Tonmoy Sarkar), as political unrest prevented my travel. A research assistant, Ann Hui Ching, helped with adding data from paper forms into the database. In the UK, I conducted the cognitive interviews and the British HIV Association, the British Association for Sexual Health and HIV, and HIV i-Base supported with survey dissemination. Dr Kondwani Mughogho, a psychometrician at the University of Cambridge, reviewed my statistical analysis plan and code. The final tools reflect input from the research team, contributing experts, and affected community members.

The children's book mentioned in the discussion was co-written with co-investigator Dr Kkunsa Hadson, and illustrated by Ugandan illustrator Paul Wembabazi. My supervisor, Dr Ashleigh Cheyne, and the Walimu project lead, Olive Kabajaasi, assisted with production. Representatives from the Ministry of Health Uganda, Walimu collaborators, and Professor Elleke Boehmer (Professor of World Literature, University of Oxford) reviewed the book.

4.2 Introduction

4.2.1 Background

Although the drivers and intensity of stigma vary by disease and setting, similarities in its core manifestations have been repeatedly observed.[19,25,87,89,90] As highlighted in previous chapters, this creates an opportunity for transferable solutions.

Experts in the field have repeatedly recommended more harmonised approaches to stigma assessment. In 2006, Van Brakel[89] proposed that, based on commonalities in manifestations, stigma instruments should be adapted and validated for generic use where possible. He and Galarza later emphasised the public health advantages of using joint strategies, including strengthening the cumulative evidence base and optimising the use of available resources.[19] Likewise, Stangl et al.[25] have called for greater alignment in stigma measurement, stressing the need for cross-disciplinary and cross-disease research that strengthens the collective ability to address stigma. Gavan et al.[90] recently echoed this, positing that there is a particular demand for strong quantitative tools to complement existing qualitative work. They specify that these tools should be theory-driven, psychometrically sound, and usable in resource-constrained settings.[90]

A cross-cutting approach to stigma assessment has been successfully implemented for chronic diseases,[187] but comparable efforts for acute infectious disease outbreaks are lacking. The unpredictability of infectious disease outbreaks makes the case for cross-cutting solutions even stronger. As illustrated in Chapter 2, without these, each response has to begin with building new tools, delaying assessment and slowing the uptake of lessons learned, by as much as two years in some cases.

It is considered best practice to test potential scale items (i.e. individual questions) in a sample that reflects the heterogeneity of the intended target population.[81]

This research is therefore situated across three outbreak settings: Ebola disease in Uganda, mpox in the UK, and Nipah virus disease in Bangladesh. Each of these contexts is briefly introduced below.

Ebola disease in Uganda

Ebola disease, caused by filoviruses of the *Orthoebolavirus* genus, is transmitted through contact with bodily fluids of infected animals or people.[188] It presents with an acute febrile illness that may progress to multi-organ involvement and haemorrhagic complications.[188] Of the known species, Sudan virus has most frequently affected Uganda since the country's first outbreak in 2000.[189] In September 2022, Sudan virus was detected in central Uganda, marking the country's seventh Ebola disease outbreak.[189] The outbreak resulted in 164 cases and 77 deaths (case fatality ratio: 47%), making it Uganda's second largest Ebola disease outbreak on record.[189] The districts of Mubende and Kassanda were predominantly affected.[189] The end of the outbreak was declared in January 2023, with a subsequent outbreak in early 2025.[190] There are currently no licensed vaccines or therapeutics for Sudan virus.[188] In West Africa and the DRC, stigma has been repeatedly identified as a barrier to Ebola disease control and community re-integration.[125,153,191–194] In contrast, research on Ebola-related stigma in Uganda is limited.[195]

Mpox in the UK

Mpox, caused by the monkeypox virus (MPXV) of the *Orthopoxvirus* genus, is transmitted through close contact and typically presents with a rash or mucosal lesions, accompanied by non-specific systemic symptoms.[196] Mpox has been a concern in affected regions of Africa for decades.[196] However, in 2022 a growing number of clade IIb cases were reported globally.[197] This prompted the WHO to declare the first of two successive Public Health Emergencies of International Concern, with the second declared due to a surge of clade I MPXV (including a new subclade Ib) in the DRC and other African countries (August 2024 – September 2025).[197] The UK was among the first countries to detect clade IIb, and as of October

2025, has had over 4,300 confirmed cases, with no reported deaths.[197] A distinctive feature of the clade IIb outbreak in newly affected countries, including the UK, was sustained transmission during sexual contact primarily within, but not restricted to, networks of gay, bisexual, and other men who have sex with men (GBMSM).[198] Mpox vaccines for pre- and post-exposure prophylaxis have been available in the UK since June 2022 but there is no proven effective antiviral treatment.[196] Mpox-related stigma has been noted as a prominent concern across contexts, with reports of it impacting care-seeking experiences and self-perception.[198]

Nipah virus disease in Bangladesh

Nipah virus, a paramyxovirus of the *Henipavirus* genus, causes illness in humans ranging from mild symptoms to acute respiratory distress and fatal encephalitis.[199–201] First identified in pig farmers in Malaysia in 1998, it has since caused almost yearly outbreaks in Bangladesh, with over 350 reported cases and an estimated case fatality ratio of 74% (as of December 2024).[200] Most outbreaks in Bangladesh are linked to consumption of raw date palm sap contaminated by fruit bats, but human-to-human transmission is also documented, raising concern about epidemic potential.[200,201] This concern is heightened by the lack of licensed vaccines or therapeutics.[200,201] While there is a growing body of biomedical research on Nipah virus,[202] research on stigma and other social consequences remains sparse, with only brief mentions of survivor ostracisation.[48,199,203]

4.2.2 Objectives

This chapter relates to Objectives 3 and 4 of the thesis, which are to:

- Design stigma assessment tools that are broadly applicable in a wide range of outbreaks, and
- Validate the assessment tools in three outbreak-affected communities

4.3 Methods

4.3.1 Methods overview

The methods in this chapter followed the best practices proposed by Boateng et al.[81] for developing and validating scales in health, social, and behavioural research. They were implemented in four iterative phases (Figure 4.1).

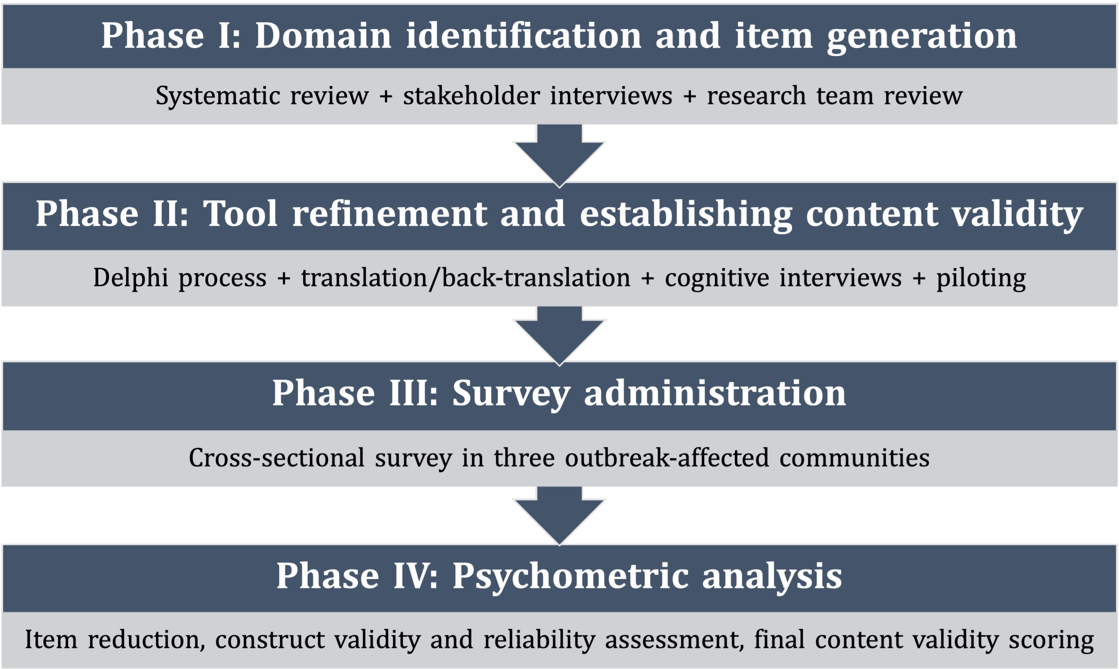

Figure 4.1: Overview of methods used for development and evaluation of stigma assessment tools

4.3.2 Rationale for methods

This work was designed to maintain the rigour of established best practices while accounting for practical constraints. An online Delphi was used to gather expert feedback, rather than consensus meetings or individual consultation, to accommodate for experts' limited availability and time zone differences. This format also helped to mitigate the influence of power dynamics that can emerge in group discussions. Cognitive interviewing was used for community feedback as it allowed for rapport building and detailed discussion.

The survey was developed across the three sites (Uganda, UK, and Bangladesh) in parallel, rather than sequentially adapted, to ensure items were robust across contexts. Non-probability quota sampling was applied as the focus was on validation across key affected groups rather than producing population-level estimates.

4.3.3 Phase I: Domain identification and item generation

The first phase of tool development involved defining the domains (i.e. dimensions of stigma) to be assessed and drafting potential items to capture them. Defining domains at the outset helps ensure that a tool is theoretically grounded, rather than shaped solely by statistical patterns observed in later analyses.[81]

This process was informed by the results of the systematic review (Chapter 2) and stakeholder interviews (Chapter 3). It began by compiling a working list of stigma domains for assessment (Appendix C.1). Actors (i.e. those noted to enact stigma) were grouped into broad categories (Figure 4.2). Self stigma was hypothesised to be a separate construct resulting from the internalisation of the other forms of stigma, rather than a sub-category. Social stigma was noted to differ during an illness (initial social stigma) and after recovery (enduring social stigma).

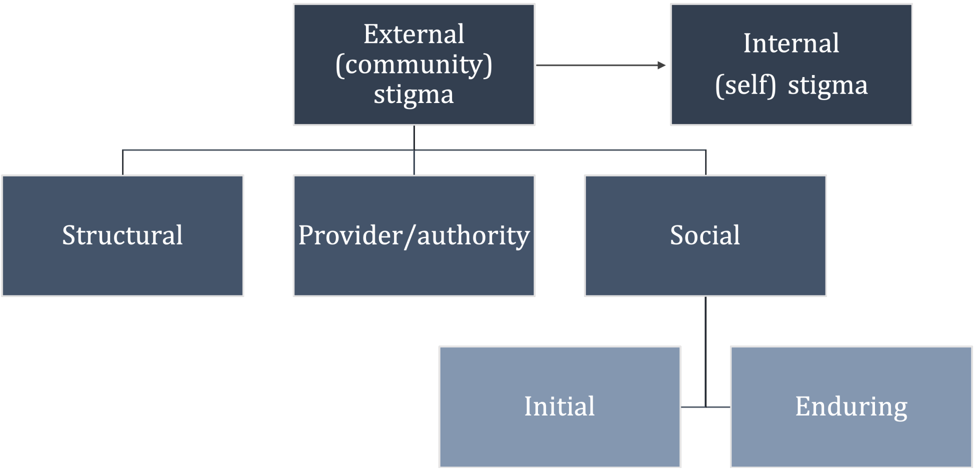

Figure 4.2: Stigma types by actor

Eight members of the research team, including two community co-investigators, agreed on the tool structure and drafted potential items. Item development was based on three criteria: (a) conceptual relevance, (b) cross-contextual applicability, and (c) simplicity of language. In line with stakeholder recommendations, items were distanced from the respondent where possible (i.e. phrased in the third person) to minimise social desirability bias and sensitivity. For instance, items were phrased as ‘People who have Nipah are looked down on’ rather than ‘I look down on people who have Nipah’ (further details in Appendix C.2).

4.3.4 Phase II: Tool refinement and establishing content validity

Delphi process

Items were refined through two rounds of feedback in a Delphi process involving a multidisciplinary panel of experts. For this process, ten outbreak response and/or stigma experts were identified from each WHO region (60 in total) through a literature search and institutional networks. Invitations to contribute were sent via email. A total of 41 experts contributed to at least one feedback round, with representation from all WHO regions (Appendix C.3). Ten interviewees from

Chapter 3 were included in the expert panel to ensure continuity of stakeholder input.

During the Delphi rounds, experts scored the clarity, relevance, and comprehensiveness of draft items, survey instructions, and response options using a 4-point content validity index (CVI) (e.g. relevance scored from 1 = not relevant to 4 = highly relevant) (Appendix C.4). Qualitative feedback was provided for lower scores. The format and items were revised following each round based on this feedback.

Based on the feedback from the Delphi, two separate stigma assessment needs were identified: (1) a brief tool for recognition and repeat evaluation of stigma during an outbreak, and (2) a more detailed tool for in-depth understanding of causes, manifestations and impacts of this stigma. The survey content was therefore formatted into two separate components to address these needs: (1) a set of short scales, referred to as the (Re)-emerging And ePidemic Infectious Diseases (RAPID) Stigma Scales, and (2) a readily-adaptable modular mapping tool, referred to as the Stigma Survey and Community-based Assessment for New and Re-emerging outbreaks (Stigma-SCANR) (Figure 4.3).

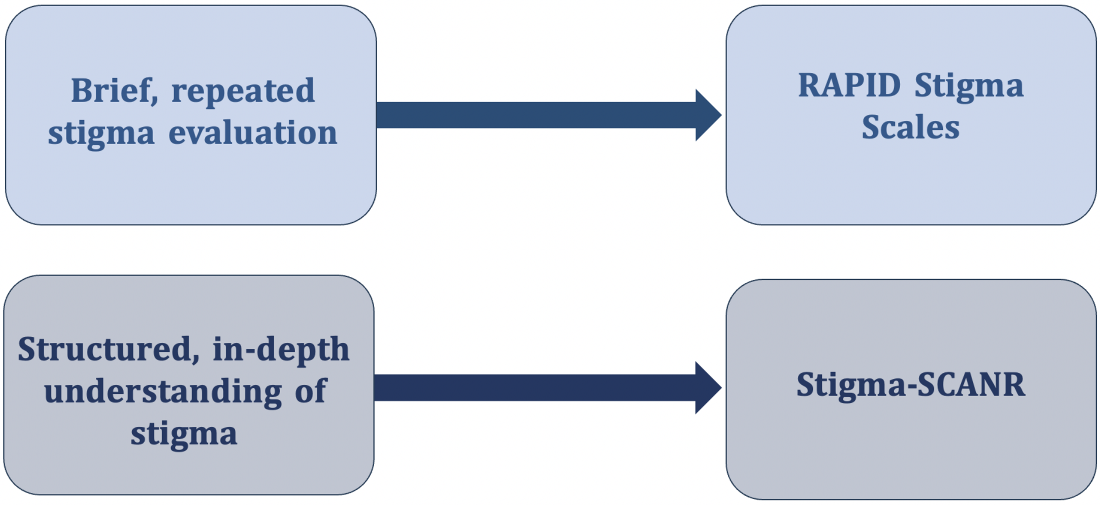

Figure 4.3: Stigma assessment needs and corresponding tools

Translation and back-translation

The tools were translated into Luganda for use in central Uganda and Bengali for use in Bangladesh, following ISPOR guidelines.[204] This included two independent forward translations for each language, reconciliation, back-translation, and review with local fieldwork leads.

Cognitive interviews and piloting

The content was further refined through cognitive interviews with community members affected by each outbreak (Appendix C.5). During this process, interviewees described their initial thoughts in response to each survey question (think aloud technique) and answered follow-up questions to explore how items were interpreted (probing technique). The survey was iteratively adapted until no confusion or concerns were identified. Saturation was reached after 10–16 interviews per site.

Changes arising from the cognitive interviews included adjusting the phrasing, response options, and order of items, and establishing where context-specific questions were required (e.g. vaccination was considered important to ask about for mpox). Open-ended questions were added at the end of the survey to capture stigma narratives, as these were often spontaneously offered during interviews.

Following cognitive interviewing, the survey was piloted with 31 respondents in the UK to test practical aspects of administration. For the RAPID Scales, there was an initial preference for the three-point response format 'Yes, Sometimes, No', but during piloting this had poor discriminatory ability ($> 70\%$ = 'sometimes'). It was therefore changed to the four-point scale 'Yes, Probably, Unlikely, No', following discussion with community-based collaborators across the three sites.

4.3.5 Phase III: Survey administration

Study population and sampling strategy

The final survey was administered in the same contexts as the cognitive interviews. A minimum of 300 respondents were recruited per site. This aligns with scale validation recommendations that suggest either 10 respondents per item or a minimum of 300 respondents, irrespective of item number, as the threshold for stable factor analysis.[81,205] Quota sampling ensured representation of recovered persons, household members/close contacts, clinical care providers, outbreak response support staff, and other affected community members.

Respondents were eligible if they a) were 18 years or older, b) lived in an area affected by the outbreak, c) were aware of the outbreak of concern, d) spoke a language the survey was available in, and e) were able to provide informed consent.

Recruitment and administration

Recruitment and administration methods were tailored to each context. In the UK, recruitment was conducted online via the Prolific survey platform, social media, and institutional mailing lists of sexual health professional networks and local HIV and LGBTQ+ organisations, as these population groups were considered most affected at the time of survey administration.[206] All UK surveys were self-administered.

In Uganda and Bangladesh, respondents were recruited through survivor support services, community leaders, village health teams, and hospital leadership. Surveys were administered by local data collectors following training. Surveys were administered in English and Luganda in Uganda depending on respondent preference, English in the UK, and Bengali in Bangladesh. During survey administration, any items that respondents had difficulty answering were flagged and the reason documented.

Surveys were conducted online using Research Electronic Data Capture (REDCap) where feasible, with paper-based forms used in areas with limited internet access. Data collection occurred between March and September 2024. Further site-specific details are available in Appendix C.6.

4.3.6 Phase IV: Psychometric analysis

Psychometric analyses were performed to establish the RAPID Scales as composite measures and evaluate whether they reliably and accurately measured the underlying stigma constructs. All analyses were performed using R statistical software version 4.4.2[207] (psych,[208] GPArotation,[209] lavaan,[210] semTools,[211] and survey packages[212]), with statistical significance set at $p < 0.05$.

Data cleaning and missing data

Data cleaning involved removing ineligible respondents, incomplete surveys, and responses that failed either of two attention checks in the online version of the survey (details available in Appendix C.7). Missing data were minimal ($\leq 0.5\%$ across all variables) and primarily from paper-based forms used in areas with limited internet access. Missingness was therefore handled using listwise deletion (i.e. cases with all relevant data were used for each analysis).

Descriptive and response distribution analyses

The study population is described using standard descriptive statistics, with measures of central tendency and variability reported for continuous variables, and frequencies and percentages for categorical variables.

Likert-scale responses were treated as ordinal data, and scale mean scores as continuous data. Response distributions were examined, and items flagged for removal if they met the following predefined criteria: floor or ceiling effects $>$ 80%, skewness outside the range of -1 to 1, absolute kurtosis $>$ 7, adjacent item endorsement frequencies $<$ 10%, or inter-item correlations $>$ 0.8.[213]

Internal structural validity: exploratory and confirmatory factor analyses

The dataset was randomly split into two equally sized samples for exploratory factor analysis (EFA) and confirmatory factor analysis (CFA), ensuring equal representation of the three outbreak contexts and adequate sample size for scale validation in each. This allowed the underlying factor structure (i.e. different dimensions of stigma) to be explored in the EFA without assumptions, and then independently tested in a separate sample during CFA.

Data suitability for factor analysis was confirmed using the Kaiser-Meyer-Olkin (KMO) measure and Bartlett's test of sphericity. A KMO $>$ 0.8 and a significant Bartlett's test were considered sufficient evidence that correlations among items were adequate to justify factor analysis.[214,215]

EFA was conducted using unweighted least squares extraction to account for the ordinal nature of the data. Promax rotation was applied as factor correlations were anticipated. The optimal number of factors was determined by parallel analysis and the Empirical Kaiser criterion. Items with cross-loadings $>$ 0.3 or communalities $<$ 0.4 were removed one at a time, with the EFA rerun after each removal. This process continued until all items had single factor loadings $>$ 0.4. 95% confidence intervals for factor loadings were obtained via bootstrapping (n = 1000) with Procrustes rotation to align factors across resamples.

CFA was performed to confirm the factor structure identified in the EFA, and assess internal structural validity (as defined in Table 2.2). The weighted least squares means and variance-adjusted estimator was used due to the ordinal and non-normally distributed nature of the data. Model fit was evaluated using global fit indices including the scaled comparative fit index (CFI), root mean square error of approximation (RMSEA), and standardised root mean square residual (SRMR). Residual correlation matrices and modification indices were examined to assess local fit, while considering theoretical justifications to avoid overfitting. The final models were selected based on statistical fit, parsimony, and interpretability.

To assess the impact of non-probability sampling on the results, a weighted CFA was conducted as a sensitivity analysis for each scale. Sampling weights, based on estimated population sizes for each respondent category, were applied to account for unequal selection probabilities. Fit indices and factor loadings were then compared between the weighted and unweighted models (Appendix C.8).

Reliability and external construct validity

Scale internal consistency (i.e. within-scale reliability) was assessed using ordinal alpha (with Cronbach's alpha and hierarchical omega reported in Appendix C.9). External construct validity was assessed through regression analyses testing predefined hypotheses with variables of public health consequence. Multiple logistic regression was used to test the relationship between stigma scores and care-seeking hesitancy. Multiple linear regression was used to examine associations with symptom-reporting hesitancy, acceptance of recovered persons, and the relationship between community and self stigma (measure details in Appendix C.10). All models controlled for age, gender, study site, urban/rural residence, outbreak responder status, prior diagnosis, close relationships with recovered individuals, and self-reported understanding of the illness. Multicollinearity (i.e. excessive correlation among predictors) was excluded by examining variance inflation factors (all were < 10).

Content validity

Content validity was initially established through the tool development and refinement process, including the cognitive interviews, which focused on optimising clarity, relevance, and comprehensiveness across study sites. To calculate final CVI scores, experts who participated in both initial Delphi rounds were invited to complete a final round, rating the face validity, relevance, and comprehensiveness of each item or component for both the RAPID Scales and Stigma-SCANR.

4.3.7 Patient and public involvement and engagement

Two community co-investigators with lived experience of mpox and Ebola disease were involved as part of the research team from the study's conceptualisation to dissemination of results. Recovered patients and other members of affected communities were included as expert panellists in the Delphi process. Cognitive interviews with affected community members helped to direct and refine the tools. Across all sites, study plans were discussed with key community members and leaders to ensure transparency and appropriateness before starting data collection.

4.3.8 Ethical considerations

This study was approved by the University of Oxford's Medical Sciences Division Ethics Committee (reference: R87722/RE004), Makerere University School of Public Health Research Ethics Committee (SPH-2024-577), Uganda National Council for Science and Technology (SS2727ES), and International Centre for Diarrhoeal Disease Research, Bangladesh Research and Ethical Review Committees (PR-

23128). Respondents provided informed consent prior to starting the survey. The details of relevant local psychosocial support networks were provided to respondents. Appropriate reimbursement in each study context was determined with the local collaborators and ethics committees. The expert Delphi process was deemed exempt from formal ethical approval following consultation with the University of Oxford's Medical Sciences Division Ethics Committee.

4.4 Results

4.4.1 Survey respondent characteristics

A total of 1,038 respondents started the final survey across the three sites. After excluding two ineligible respondents, 12 incomplete surveys, and 16 online surveys with failed attention checks, 1,008 eligible respondents completed the survey. At the interviewer-administered sites, three individuals declined to participate citing time constraints. Respondent characteristics are detailed in Table 4.1.

Table 4.1: Respondent characteristics by study site

Characteristic	**Uganda (Ebola, N=302)**	**UK (mpox, N=406)**	**Bangladesh (Nipah, N=300*)**
Age			
Median (IQR; range), N	32 (27-40; 18-76), 302	32 (26-40; 18-78), 406	36 (30-43; 18-78), 298
Gender			
Woman	159/302 (52.6)	69/406 (17.0)	146/296 (49.3)
Man	143/302 (47.4)	288/406 (70.9)	150/296 (50.7)
Other#	0/302 (0.0)	49/406 (12.1)	0/296 (0.0)
Nature of residence			
Urban	130/302 (43.0)	264/406 (65.0)	103/300 (34.3)
Rural	172/302 (57.0)	142/406 (35.0)	197/300 (65.7)
Proximity to illness&			
Personal lived experience of illness	51/302 (16.9)	13/406 (3.2)	30/300 (10.0)

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Table 4.1 – continued from previous page

Characteristic	Uganda (Ebola, N=302)	UK (mpox, N=406)	Bangladesh (Nipah, N=300*)
Close relationship with someone who had illness	208/302 (68.9)	37/406 (9.1)	81/300 (27.0)
Clinical care providers	49/302 (16.2)	112/406 (27.6)	60/300 (20.0)
Outbreak response support staff	61/302 (20.2)	18/406 (4.4)	30/300 (10.0)
Other community member	55/302 (18.2)	262/406 (64.5)	115/300 (38.3)
Self-reported understanding of disease			
Heard of it but don't know details	39/302 (12.9)	162/406 (39.9)	162/299 (54.2)
Know basic details	152/302 (50.3)	212/406 (52.2)	111/299 (37.1)
Know more than the basics	111/302 (36.8)	32/406 (7.9)	26/299 (8.7)

This table presents demographic and contextual characteristics of respondents who received the full survey (containing RAPID scale items and Stigma-SCANR items) across the three study sites. Data are count/total (valid %). *Denominators vary with completeness of the data. &Respondents may be included in more than one category, #In the UK cohort this included 43 respondents who identified as non-binary, four respondents who specified another gender, and two respondents who selected prefer not to say. N = total respondents, IQR = interquartile range.

4.4.2 RAPID Stigma Scales

Overview of content and exploratory analyses

Twenty-four draft RAPID scale items were field-tested (Appendix C.11). After iterative analysis, 12 items were retained for the RAPID Community Stigma Scale and four items were retained for the RAPID Self Stigma Scale (Table 4.2).

Table 4.2: Final RAPID Community and Self Stigma Scale structure, items, and response options

Item No.	Item: People who have [X disease] are...	3 = Yes	2 = Probably	1 = Unlikely	0 = No
RAPID Community Stigma Scale					
Initial social stigma					
C1	looked down on	☐	☐	☐	☐
C2	gossiped about	☐	☐	☐	☐
C3	treated unkindly by the public (including online/on social media)	☐	☐	☐	☐

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Table 4.2 – continued from previous page

Item No.	**Item: People who have [X disease] are. . .**	**3 = Yes**	**2 = Probably**	**1 = Unlikely**	**0 = No**
Provider/authority-related stigma					
C4	negatively judged by healthcare workers	☐	☐	☐	☐
C5	portrayed negatively in the media	☐	☐	☐	☐
C6	spoken about negatively by politicians	☐	☐	☐	☐
Structural stigma					
C7	denied certain rights	☐	☐	☐	☐
C8	at risk of losing work or education opportunities	☐	☐	☐	☐
C9	not welcome in certain places after recovery	☐	☐	☐	☐
Enduring social stigma					
C10	likely to have more difficulty finding a partner after recovery	☐	☐	☐	☐
C11	at risk of losing customers after recovery if they have a business	☐	☐	☐	☐
C12	rejected by their community	☐	☐	☐	☐
RAPID Self Stigma Scale					
S1	going to try to keep the diagnosis a secret	☐	☐	☐	☐
S2	ashamed of the diagnosis	☐	☐	☐	☐
S3	hesitant to seek medical care for their illness	☐	☐	☐	☐
S4	likely to believe they deserved the illness	☐	☐	☐	☐

Scale instructions read: “Please answer the questions based on what you have experienced, seen, or heard in your community [in a defined time period appropriate for the outbreak and research aim]. For this survey, your community means all the people you regularly interact with.”

Three of the initial 24 items were excluded due to repeated clarity concerns raised during data collector debriefing sessions. An additional item was removed due to concerns about cross-contextual relevance and a correlation > 0.8 with a more broadly applicable item (Appendix C.11). All other items had acceptable response distributions.

The correlation matrix revealed conceptually distinct clusters among the community stigma items, while self stigma items displayed broader correlations (Appendix

C.12). This pattern aligned with the conceptualisation of self stigma as a distinct construct stemming from community stigma, rather than as a sub-factor within it. The community stigma and self stigma items were therefore analysed separately.

A significant Bartlett's test of sphericity and a KMO > 0.8 for both the community and self stigma EFA datasets confirmed their suitability for factor analysis (Appendix C.13). Guided by the preliminary factor number analyses, EFA yielded a stable and interpretable four-factor, 12-item model for community stigma after five iterations. A four-item self stigma model was obtained after two iterations (Appendix C.13).

Construct validity and reliability

CFA and model comparison analyses supported a second-order (two-level) structure for community stigma and a unidimensional (single factor) model for self stigma. Both models showed excellent statistical fit (community: CFI = 0.99, RMSEA = 0.04, SRMR = 0.04; self: CFI = 1.00, RMSEA < 0.01, SRMR = 0.01). This was consistent with the *a priori* conceptual framework (see Appendix C.14 for path diagrams, and Appendix C.15 for model comparisons). The fit indices remained acceptable when examined separately for the three cohorts (Appendix C.16). The internal structural validity of both scales was supported by strong item loadings on their intended factors (Table 4.3). This suggests that the items are adequate indicators of the underlying dimensions. Item-level statistics for each study cohort are available in Appendix C.17.

Table 4.3: Item-level descriptive statistics and validity indicators for the final RAPID Community and Self Stigma Scales

Item: People who have [X disease] are...	**Mean (SD); median (range)**	**Est.std (95% CI)**	**R^2**	**r-CVI**
RAPID Community Stigma Scale				
F1: Initial social stigma				
C1: looked down on	1.79 (1.11); 2 (0–3)	0.76 (0.70–0.82)	0.58	1.00

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Table 4.3 – continued from previous page

Item: People who have [X disease] are...	Mean (SD); median (range)	Est.std (95% CI)	R^2	r-CVI
C2: gossiped about	2.10 (1.00); 2 (0–3)	0.64 (0.58–0.71)	0.42	0.97
C3: treated unkindly by the public (including online/on social media)	1.65 (1.07); 2 (0–3)	0.82 (0.77–0.88)	0.68	0.97
F2: Provider/authority-related stigma				
C4: negatively judged by healthcare workers	0.78 (0.95); 0 (0–3)	0.72 (0.65–0.79)	0.52	0.91
C5: portrayed negatively in the media	1.18 (1.12); 1 (0–3)	0.87 (0.82–0.92)	0.76	0.91
C6: spoken about negatively by politicians	0.92 (1.00); 1 (0–3)	0.78 (0.72–0.84)	0.61	0.88
F3: Structural stigma				
C7: denied certain rights	1.21 (1.08); 1 (0–3)	0.80 (0.76–0.84)	0.70	0.97
C8: at risk of losing work or education opportunities	1.47 (1.07); 2 (0–3)	0.88 (0.85–0.92)	0.78	0.97
C9: not welcome in certain places after recovery	1.42 (1.07); 2 (0–3)	0.84 (0.80–0.87)	0.64	0.94
F4: Enduring social stigma				
C10: likely to have more difficulty finding a partner after recovery	1.52 (1.10); 2 (0–3)	0.86 (0.83–0.90)	0.75	0.94
C11: at risk of losing customers after recovery if they have a business	1.55 (1.10); 2 (0–3)	0.88 (0.85–0.91)	0.78	0.88
C12: rejected by their community	1.20 (1.08); 1 (0–3)	0.86 (0.82–0.89)	0.73	0.97
Overall	1.40 (0.72); 1.42 (0–3)	NA	0.66	0.94
RAPID Self Stigma Scale				
S1: going to try to keep the diagnosis a secret	1.51 (1.14); 2 (0–3)	0.78 (0.73–0.83)	0.61	0.97
S2: ashamed of the diagnosis	1.47 (1.17); 2 (0–3)	0.82 (0.78–0.86)	0.67	1.00
S3: hesitant to seek medical care for their illness	1.36 (1.12); 2 (0–3)	0.77 (0.72–0.82)	0.59	1.00
S4: likely to believe they deserved the illness	0.86 (0.96); 1 (0–3)	0.60 (0.54–0.67)	0.36	0.94
Overall	1.30 (0.85); 1.50 (0–3)	NA	0.56	0.98

Mean, standard deviation (SD), median, and range are reported for each item. Standardised factor loading estimates (est.std) with 95% confidence intervals (CI) are based on confirmatory factor analysis, with squared multiple correlations (R^2) indicating variance explained. The relevance content validity index (r-CVI) reflects expert ratings from the final panel of 34 experts on a 4-point Likert scale (3 = Yes, 2 = Probably, 1 = Unlikely, 0 = No) with > 0.8 adequate and > 0.9 excellent[216]; factor and overall scores are calculated as the mean (SD) and median (range) of all relevant items within each scale.

Residual correlations were small in both models. In the self stigma model all were

< 0.10, and in the community stigma model two exceeded 0.10 but remained $<$ 0.15 (Appendix C.18). This indicates that there were no substantial associations between items beyond those accounted for by the factors. All modification indices (i.e. statistical suggestions for adding extra paths) were below 15, suggesting no major local misfit, and no model adjustments were required based on theoretical considerations.

In the sensitivity analyses, the weighted CFA models retained strong fit thresholds (CFI > 0.95; RMSEA < 0.05), and all factor loadings remained > 0.5. This suggests that the non-probability sampling had limited impact on the scale validity findings (Appendix C.8).

In terms of reliability, both scales demonstrated good internal consistency, indicating that items within each scale were measuring the same underlying concept in a consistent way (ordinal alphas: 0.79–0.90 for Community Stigma subscales; 0.83 for Self Stigma) (Table 4.4). Additional reliability metrics are presented in Appendix C.9.

External construct validity was supported by the outcomes of multiple regression analyses, which confirmed that stigma scores behaved in line with predefined expectations. Higher scores on both scales predicted greater symptom-reporting hesitancy (community: $\beta = 0.21$, $p < 0.001$; self: $\beta = 0.19$, $p < 0.001$) and care-seeking hesitancy (community: odds ratio (OR) = 1.63, $p < 0.001$; self: OR = 1.71, $p < 0.001$). Higher community stigma also significantly predicted lower acceptance of recovered persons ($\beta = -0.22$, $p < 0.001$) and higher self stigma ($\beta = 0.72$, $p < 0.001$) (Table 4.4, Appendix C.19).

Table 4.4: Psychometric properties of the final RAPID Community and Self Stigma Scales

Psychometric property	Criteria for acceptability	Community Stigma Scale (F1, F2, F3, F4)	Self Stigma Scale
Content validity			
Face validity*	> 0.8	0.97	1.00
Relevance (r-CVI)	> 0.8	0.94	0.98
Comprehensiveness (c-CVI)	> 0.8	0.97	1.00
Clarity content validity	*Adequate: Assessed qualitatively through cognitive interviews*		
Internal structural validity			
Model fit (CFI scaled)	> 0.95	0.99	1.00
RMSEA (90% CI)	< 0.06	0.04 (0.02–0.05)	< 0.01 (0.00–0.08)
SRMR	< 0.08	0.04	0.01
Average variance extracted	> 0.5	0.68 (0.56, 0.63, 0.71, 0.75)	0.56
External construct validity			
Multiple linear regression → Symptom-reporting hesitancy	> 0; $p < 0.05$	0.21 (0.15, 0.27), $p < 0.001$	0.19 (0.13, 0.24), $p < 0.001$
Multiple logistic regression → Care-seeking hesitancy	> 0; $p < 0.05$	1.63 (1.22, 2.19), $p < 0.001$	1.71 (1.33, 2.21), $p < 0.001$
Multiple linear regression → Social acceptance of recovered persons	< 0; $p < 0.05$	-0.22 (-0.32, -0.12), $p < 0.001$	NA
Multiple linear regression → Self stigma	> 0; $p < 0.05$	0.72 (0.66, 0.77), $p < 0.001$	NA
Reliability			
Internal consistency (ordinal alpha)	0.70–0.95	0.92 (0.79, 0.83, 0.88, 0.90)	0.83

*Face validity score = proportion of respondents who agreed or strongly agreed with the statement "On face value, these items seem like a valid measure of external community stigma/self stigma". r-CVI = relevance content validity index (average); c-CVI = comprehensiveness content validity index (average); CFI = Comparative Fit Index; RMSEA = Root Mean Square Error of Approximation; CI = confidence interval (90% CI reported for RMSEA as per structural equation modelling convention); SRMR = Standardised Root Mean Square Residual; F1 = initial stigma subscale; F2 = provider/authority-related stigma subscale; F3 = structural stigma subscale; F4 = enduring stigma subscale; → = dependent variable.

4.4.3 Stigma-SCANR

Overview of modules and content validity scores

The final Stigma-SCANR contains 9 modules and covers all major domains of the Hourglass Stigma Model developed in Chapter 3 (Appendix C.20). The overall survey CVI (average content validity score across all modules) was 0.99 for relevance and 1.00 for comprehensiveness, representing 'excellent' content validity.[216] An overview of the content and CVI scores for each module are provided in Table 4.5. Further validation was not applicable since the tool was intended for mapping rather than developing composite scores.

Table 4.5: Final content validity scores

Module Number	Module content	Expert relevance CVI score	Interpretation
1	Care-seeking and stigma	1.00	Excellent
2	Beliefs and feelings	1.00	Excellent
3	Anticipated social stigma	1.00	Excellent
4	Anticipated structural stigma	1.00	Excellent
5	Personal experiences of stigma	1.00	Excellent
6	Concerns about sharing diagnosis and social acceptance of others	0.97	Excellent
7	Stigma by association	1.00	Excellent
8	Stigma reduction	0.97	Excellent
9	Stigma narratives	0.97	Excellent

CVI = content validity index; interpretation: > 0.8 considered adequate; > 0.9 considered excellent.[216]

Stigma-SCANR applied example 1: Context-specific mapping

Figure 4.4 illustrates how the Stigma-SCANR can be used to map stigma in a specific context, using anticipated Ebola disease stigma results from central Uganda as an example.

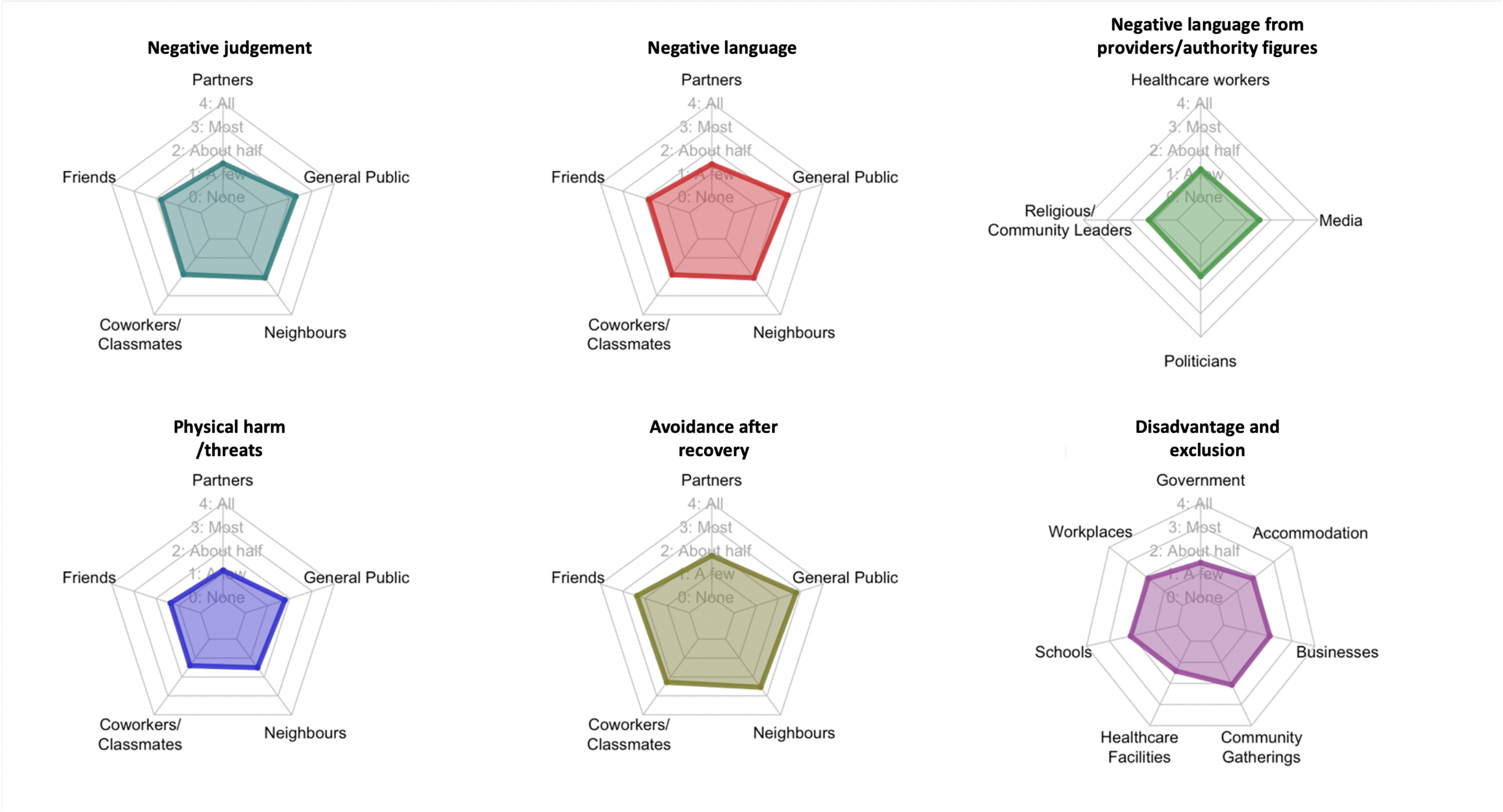

Figure 4.4: Applied example of Stigma-SCANR results (Module 2 & 3): Anticipated Ebola disease stigma in central Uganda. Respondents were presented with a scenario in which someone in their community was diagnosed with Ebola. They were then asked to estimate what proportion of the community would enact various forms of stigma. Radar charts show mean scores on the response scale of none (0) to all (4) for different actors. Larger plots indicate more anticipated stigma.

In this setting, avoidance after recovery was the most widely anticipated form of stigma, with the general public considered the mostly likely to enact stigma across manifestations. Schools were the setting considered most likely to disadvantage or exclude a person recovered from Ebola disease. Concerns about school-based stigma were reiterated in the open-text responses.

> *"School teachers didn't treat my children well because I was an Ebola patient."* – Respondent 299, Ebola survivor, Kassanda district

Stigma-SCANR applied example 2: Support for stigma reduction interventions across outbreak contexts

The Stigma-SCANR also assesses community endorsement of stigma reduction measures (Module 8). Table 4.6 presents levels of support for stigma reduction measures across Uganda, the UK, and Bangladesh. Across all three cohorts, public education, awareness campaigns, thoughtful health messaging, and survivor testimony were the most supported measures. Increased psychological support received moderate endorsement, while recovery certificates and laws to prevent discrimination were consistently the least supported. The greatest difference across contexts was between support for recovery certificates for Ebola disease in Uganda (72%) and mpox in the UK (19%).

Table 4.6: Community support for stigma reduction measures across Ebola disease, mpox, and Nipah virus disease outbreaks

Stigma reduction measure	**No. respondents in support of measure (%)**		
	Uganda (Ebola stigma) N = 302	**UK (mpox stigma) N = 406**	**Bangladesh (Nipah stigma) N = 30***
More public education	290 (96)	366 (90)	28 (93)
More awareness campaigns about stigma	259 (86)	309 (76)	24 (80)
More thoughtful public health messages	244 (81)	277 (68)	22 (73)

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Table 4.6 – continued from previous page

Stigma reduction measure	**No. respondents in support of measure (%)**		
	Uganda (Ebola stigma) N = 302	**UK (mpox stigma) N = 406**	**Bangladesh (Nipah stigma) N = 30***
Opportunities to hear the stories of people who have recovered	251 (83)	207 (51)	22 (73)
More psychological support	228 (75)	167 (41)	19 (63)
Recovery certificates	216 (72)	79 (19)	14 (47)
More laws to stop discrimination	148 (49)	149 (37)	8 (27)
Other	74 (25)	3 (1)	5 (17)
None of the above	0 (0)	14 (3)	5 (17)

*In Bangladesh this question was only asked to respondents with personal lived experience of Nipah virus disease. UK = United Kingdom

Additional suggestions in open-text responses included proposals to broaden the geographic reach of community engagement, ensure accurate and timely communication from governments and community leaders, improve responsible reporting by the media, protect survivor privacy, support reintegration into communities, and involve survivors in risk communication.

4.5 Discussion

4.5.1 Key findings in context

This chapter presents two new stigma tools: the RAPID Scales for brief assessment and the Stigma-SCANR for detailed mapping. These are the first instruments intentionally designed to assess stigma across diverse outbreaks.

Psychometric analysis of the RAPID Scales demonstrated strong construct validity, internal consistency, and predictive validity. Regression analyses provided supporting evidence of predictive relationships between stigma and important public health variables, including symptom-reporting and care-seeking hesitancy, as reported in previous studies.[57,191,217] This reinforces the utility of the scales, not only for assessing stigma, but also for anticipating its impact on outbreak control. The scales' strong performance across diverse settings demonstrated their cross-contextual applicability. It also supports observations about the shared nature of stigma manifestations across diseases.[25,87] Additionally, the factor and regression analyses support the conceptualisation of community stigma and self stigma as distinct but related constructs.[191,218,219]

4.5.2 Potential uses for stigma assessment tools

The RAPID Scales are readily deployable composite measures. They can be administered as part of rapid needs assessments to identify populations facing heightened stigma and characterise its main manifestations. This enables tailored response efforts, including communication strategies and psychosocial support. Monitoring community-level stigma dynamics can also highlight the need for specific interventions such as healthcare worker stigma training. Table 4.7 outlines the potential applications of the scales for different end-users.

The scales' brevity maximises the feasibility of data collection in time-pressured settings and allows for incorporation into broader tools such as knowledge, attitudes, and behaviour surveys. In acute outbreaks, where effective decision-making is dependent on timely data, the scales can help prioritise stigma-related concerns alongside clinical response efforts.

Table 4.7: Potential uses of the RAPID Stigma Scales

Potential end-user	**Utility (what the data could show)**	**Action (what the data could support)**
Public health authorities and policymakers	Levels and types of stigma in different communities, effects on reporting and testing, changes over time if repeated.	Prioritising areas and groups for intervention; including stigma indicators in situation reports; estimating undetected cases.[191]
Frontline response organisations	Community concerns about stigma from care providers and authority-figures, and manifestations affecting access to care or symptom reporting.	Planning community liaison; briefing and training staff; adapting household outreach, reintegration, and follow up activities.
Risk communication and community engagement teams	Perceptions of media coverage, extent of gossip and blame towards affected individuals, concerns about authority-figures or providers.	Refining the content of public messages; choosing trusted messengers; scheduling and structuring community engagement activities.
Clinical service managers	Concerns about privacy, provider-related and enduring stigma affecting healthcare service access and experiences.	Strengthening confidentiality; improving patient flow; developing staff training; adapting follow up.
Psychosocial support coordinators	Self stigma and enduring social stigma affecting acceptance after recovery.	Coordinating counselling and peer support; planning survivor follow-up; preparing return-to-school/work guidance; organising reintegration initiatives.
Community organisations and local leaders	Initial and enduring social stigma in community, structural barriers to reintegration.	Co-designing outreach; highlighting ongoing reintegration needs; mobilising community support.
Research and monitoring and evaluation teams	Baseline stigma levels, trends across communities, early signs of improvement or deterioration.	Rapid reporting of concerns; identifying the need for stigma reduction interventions in real time; evaluating community-level anti-stigma activities; documenting trends for post-response reviews and future guidance.

To facilitate straightforward interpretation, mean and median scores (0–3) are used for factor and scale totals to align with the four-point Likert scale (No/Unlikely/Probably/Yes). Thresholds for intervention should be guided by an understanding of trends and implications in the relevant context rather than fixed cut-offs. For example, even lower levels of perceived provider/authority-related stigma warrant action due to potential impact on healthcare access. Additionally, a sharp increase in scores may signal the need for urgent intervention.

As a complementary mapping tool, the Stigma-SCANR offers more detailed insights to guide the design and evaluation of stigma reduction interventions. For example, in Uganda, high levels of anticipated avoidance after recovery and school exclusion guided the development of a children's book promoting acceptance after recovery (Figure 4.5). The book was developed with a community co-investigator and Ugandan illustrator, and uses a fictional illness to maximise generalisability (Appendix C.21). It has been translated into Luganda and is currently being piloted by the Ministry of Health for dissemination in schools in central Uganda.

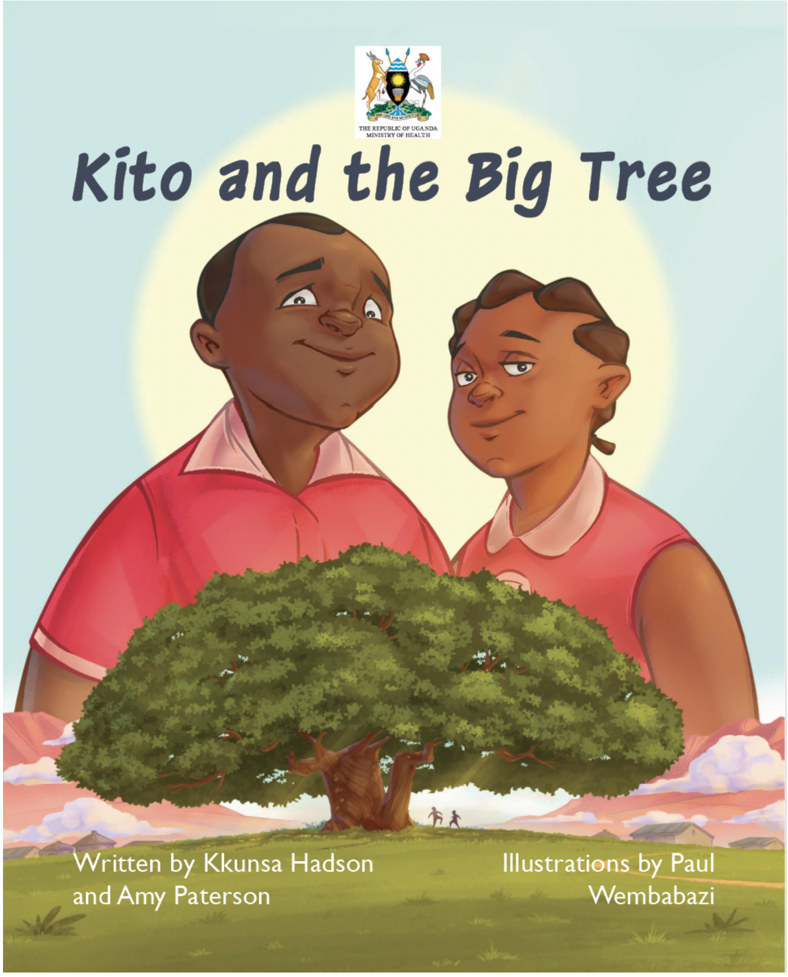

Figure 4.5: Front cover of anti-stigma children's book

Responses to the stigma reduction module offer further insights for intervention prioritisation. The consistency across all three settings reveals common community priorities, while open-text responses highlighted the value of building on existing structures such as local media channels and survivor networks. The responses also highlight affected communities' ability to contribute to intervention design. These insights provide a foundation for the development of cross-outbreak stigma reduction guidelines in Chapter 5.

The tools' validation across heterogeneous populations allows future studies flexibility in determining their sampling frame. Prior to use in new contexts, it is recommended that scales are piloted locally, and adapted if indicated. Additionally, psychosocial support or referral should be made available if involving recovered individuals. A brief user guide outlining this information is provided with the tools (Appendix C.20). The tools are available in English, Bengali, and Luganda, with additional translations in development by collaborators.

4.5.3 Strengths and limitations of the assessment tools

A core strength of both tools is that they respond directly to identified assessment needs and limitations of previous approaches. They balance transferability and ease of use in time-pressured outbreaks with capturing sufficient detail to inform decision-making. Both use distanced, indirect phrasing, which broadens the sampling frame and reduces social desirability bias and sensitivity of questions.[220] The second-order structure of the RAPID Community subscales enables sub-scores and overall scores to still be used if individual items perform poorly. The modular design of the Stigma-SCANR enables teams to adopt only the sections relevant to their context, while item-level mapping preserves granularity and permits adaptation without the need for revalidation, including by teams with limited analytic capacity.

Some of these features also have limitations. Distanced framing captures perceived stigma at the community level rather than personal experiences, which means the tools are less suited to evaluating individual-level interventions. The emphasis on transferability may also overlook context-specific forms of stigma; for example, the RAPID Scales do not capture associative stigma, which often varies by outbreak. These limitations are partly mitigated through dedicated modules on personal experiences and associative stigma in the Stigma-SCANR (Modules 5 and 7), but could be further addressed by piloting adaptations of the RAPID Scales.

Additional limitations relate to specific tools. For instance, the strong fit indices of the RAPID Self Stigma Scale may be inflated by the simplicity of the model. The brevity of the RAPID Community subscales risks reducing comprehensiveness, although three-item scales have performed well for assessing HIV stigma and loneliness.[221,222] By contrast, the detailed design of the Stigma-SCANR risks respondent fatigue. However, widely used tools such as the People Living with HIV stigma index are of a similar length.[223] Box 4.1 outlines alternative approaches to structured stigma assessment, and explains why these were not adopted.

Box 4.1: Alternative stigma assessment tool formats

In this research, distanced Likert-scale items were considered the most suitable approach to assessing stigma. However, two alternatives are noted below:

- **Vignettes** use short hypothetical scenarios to probe attitudes towards affected individuals. They have been used as an alternative means of minimising social desirability bias and optimising transferability in stigma research.[224] However, they are limited by the “spectrum critique” (i.e. they only present one ‘portrait’ of an affected person).[24] Small details, such as the names used in vignettes, often signal gender or ethnicity, which can affect responses and reinforce stigma.[24]

- **Binary approaches** code stigma as present if a respondent endorses any item from a predefined list. They have often been used to report the ‘prevalence’ of stigma.[158] While this is an appealing simplification, scholars have cautioned against viewing stigma as an either/or singular experience.[24] The complex social nature of stigma also means that a given statistic may capture vastly different dimensions, such as the proportion of the population endorsing a specific stereotype, reporting discrimination, or avoiding testing due to anticipation of stigma. Without specification, the term loses meaning and comparability across studies.

4.5.4 Methodological strengths and limitations

In developing the tools, strengths included the involvement of contributors from diverse geographic areas, which improved cross-contextual validity, and broad interdisciplinary expertise, which broadened perspectives on stigma. The equal weighting and anonymity of responses in the Delphi mitigated the influence of dominant voices, while cognitive interviews helped to ensure item clarity. In the survey phase, sampling was structured to include key subpopulations and achieved low attrition rates. The involvement of community co-investigators throughout helped to ensure the research was relevant and sensitive to lived experiences.

There are also limitations to the approaches taken. The equal weighting of Delphi responses meant that differences in expertise were not taken into account, such as variation in familiarity with stigma scales. The one-on-one structure of the cognitive interviews may have created pressure to endorse rather than critique items. In survey administration, collecting data after the local outbreak's peak in the UK, and more than a year later in Uganda, introduced potential for recall bias, and the non-probability sampling limits the generalisability of the findings.[81,205] Finally, test–retest reliability was not assessed. In the UK, where retesting would have been most feasible, it was prevented by the emergence of the Clade I mpox outbreak and shifting media narratives, which created uncertainty about the stability of findings.

4.5.5 Future research

Future research is needed to address existing limitations by assessing test-retest reliability and conducting measurement invariance analyses. The latter could allow for the comparison of mean scores across different diseases. Additionally, validating the RAPID Scales in a broader range of outbreak contexts and conducting longitudinal studies will be crucial for confirming their transferability and responsiveness to changes in stigma over time. Such efforts could demonstrate the scales' utility in evaluating stigma-reduction interventions, further strengthening their application in public health responses. While heterogeneous sampling is recommended during scale development, sub-analyses could offer valuable insights into the extent, predictors, and impact of stigma in specific contexts and populations. In future, the tools could also be adapted and validated for younger respondents.

4.5.6 Conclusions

By responding to a gap in stigma assessment, the RAPID Scales and Stigma-SCANR offer researchers, practitioners, and policymakers a means to assess stigma in a timely and systematic manner during infectious disease outbreaks. Integrating these instruments into outbreak response can improve awareness and understanding of stigma, supporting more equitable and effective outbreak control.

5

Development of anti-stigma guidelines

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5.1 Chapter preface

5.1.1 Overview

This chapter details the development of cross-outbreak anti-stigma guidelines. It draws on three sources of evidence: existing literature, stakeholder suggestions from Chapter 3, and affected community perspectives from Chapter 4. These findings are synthesised and then appraised and refined through an expert consensus process to produce guiding principles and recommended stigma reduction interventions.

5.1.2 Publication and contributions

The systematic review contained in this chapter is in preparation for journal submission and the guidelines are being prepared for publication on the International Severe Acute Respiratory and emerging Infection Consortium (ISARIC) and GOARN websites.

I conceptualised and led this component of work. GOARN and ISARIC/PSI communications officers, Rana Zianta and Isobel Young, disseminated the expressions of interest call for the expert panel. A librarian from the Bodleian Health Care Libraries, Carolyn Smith, provided input on the systematic review search strategy. Three research assistants, Chambrez-Zita Zauchenberger (CZZ), Ruan Spies (RS), and Mary Gouws (MG), helped with reviewing the literature, drafting documents, co-hosting expert meetings, and integrating feedback.

5.2 Introduction

5.2.1 Background

Although recognition of outbreak-related stigma has increased, evidence-based operational guidance for mitigating stigma remains limited. This is not to suggest that advice is absent. On the contrary, informal suggestions are numerous, and organisations frequently issue statements on stigma reduction. Scholars have also proposed interventions based on reviews of stigma reduction in non-outbreak contexts.[82,225] These serve as useful interim measures, but have a number of shortfalls.

First, the basis for this advice is often opaque. It is frequently left unspecified whether guidance reflects personal experience, anticipated net benefit, ethical principles, expert consensus, or empirical evidence. While a range of sources may be relevant, particularly in the absence of a strong evidence base, adoption is improved when implementers understand what underpins proposed actions.[226]

Second, available advice can be contradictory. For instance, a qualitative study by Crea et al.[227] suggests that community bylaws are an effective means of mitigating stigma in Ebola disease outbreaks. In contrast, a rapid review of infectious disease stigma by Gronholm et al.[225] warns that punitive or enforcement-based approaches may exacerbate stigma.

Third, terminology used in other contexts may not translate well to outbreaks. For example, The Lancet Commission on ending stigma and discrimination in mental health[59] emphasises that ‘social contact’ is the most evidence-based means of reducing stigma. This term is similarly popular in the HIV stigma literature.[228,229] In these contexts, it refers to interventions that encourage in-person or virtual interaction between people with and without a condition. This is likely to remain an effective way of fostering understanding and challenging stereotypes across contexts.

However, in outbreaks, prevailing terminology such as 'social distancing' may mean that proposals to promote 'social contact' are met with hesitation.

Another limitation of existing advice is that it is often exclusively focused on recommendations for avoiding stigmatising language. For instance, in 2020 WHO, IFRC, and UNICEF released a guide to help governments, media, and response organisations prevent and address COVID-19 stigma.[230] The guidance provides a range of helpful terminology 'do's and 'don't's and related communication strategies.[230] However, its narrow focus on language represents a missed opportunity to address many other structural and social dimensions of stigma, including disadvantage and ostracisation.

In addition, as with stigma assessment, guidance is often delayed. As a recent example, WHO guidance on preventing mpox stigma emerged six months after the start of the global outbreak.[231] Lastly, the only advice based on literature reviews predates the expansion of the field in response to COVID-19.[82,225]

Evidence-based consensus guidelines on mitigating outbreak-related stigma could serve the following purposes: (1) prompt organisations to reflect on potentially harmful practices and policies in advance of future outbreaks; (2) translate the seemingly intractable problem of stigma into actionable components; (3) align messaging and practices across actors; and (4) foreground ethical tensions and person-centred considerations in outbreak response.

5.2.2 Objectives

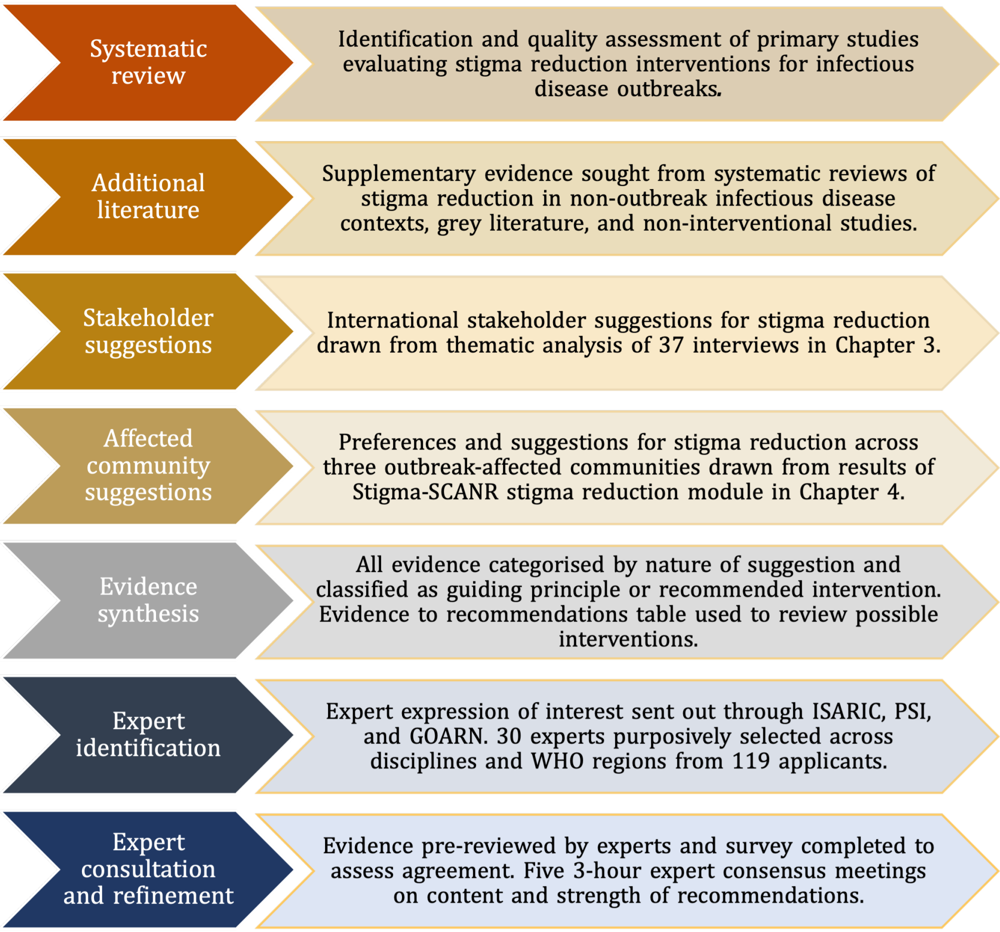
The purpose of this chapter was to develop guidance for mitigating outbreak-related stigma, in line with Objective 5 of the thesis. This involved combining evidence and expert contributions to:

a) establish a set of guiding principles for stigma prevention in the context of infectious disease outbreaks, and
b) recommend actionable interventions for organisations involved in outbreak preparedness, response, and recovery.
These were combined to form the ISARIC Anti-Stigma Guidelines.

5.3 Methods

5.3.1 Overview of methods

The methods for this chapter were informed by the WHO handbook for guideline development.[232] An overview of the process is presented in Figure 5.1.



Systematic review	Identification and quality assessment of primary studies evaluating stigma reduction interventions for infectious disease outbreaks.
Additional literature	Supplementary evidence sought from systematic reviews of stigma reduction in non-outbreak infectious disease contexts, grey literature, and non-interventional studies.
Stakeholder suggestions	International stakeholder suggestions for stigma reduction drawn from thematic analysis of 37 interviews in Chapter 3.
Affected community suggestions	Preferences and suggestions for stigma reduction across three outbreak-affected communities drawn from results of Stigma-SCANR stigma reduction module in Chapter 4.
Evidence synthesis	All evidence categorised by nature of suggestion and classified as guiding principle or recommended intervention. Evidence to recommendations table used to review possible interventions.
Expert identification	Expert expression of interest sent out through ISARIC, PSI, and GOARN. 30 experts purposively selected across disciplines and WHO regions from 119 applicants.
Expert consultation and refinement	Evidence pre-reviewed by experts and survey completed to assess agreement. Five 3-hour expert consensus meetings on content and strength of recommendations.

Figure 5.1: Overview of methods for guideline development

5.3.2 Rationale for methods

Evidence review and consensus guideline development methods were used in this chapter to translate findings from previous chapters into targeted actions. Several design decisions were informed by lessons learnt in earlier components of the work. For instance, for the expert consultation process, a broader recruitment strategy was adopted, and written feedback was combined with expert meetings to better understand varied perspectives.

5.3.3 Systematic review of interventional literature

The first phase of guideline development was a systematic review. The purpose of this phase was to identify stigma reduction interventions with direct evidence of effectiveness in outbreaks. The review protocol was prospectively registered (PROSPERO record number CRD420251007553).

The search strategy covered Medline, Embase, PsycINFO, and Global Health databases, using key terms for 'stigma' or 'social reintegration' and 'outbreaks' (Appendix D.1). The search was run on 11 March 2025 without date or language restrictions. This was supplemented by reference list screening of related systematic reviews and included studies. Eligible studies were peer-reviewed and used qualitative and/or quantitative methodologies to evaluate stigma reduction interventions (full eligibility criteria in Appendix D.2).

Retrieved citations were uploaded to Rayyan systematic review software[118] and deduplicated. Screening and data extraction were undertaken by three reviewers (CZZ, RS, and myself), with independent double screening and meetings to resolve discrepancies after every 10% of records. As in Chapter 2, this process continued until 'excellent' inter-rater agreement was reached between all reviewing pairs ($\kappa > 0.75$).[119] This was achieved after the third round of title and abstract screening and first round of full-text screening, after which all remaining citations were divided between reviewers.

A Microsoft Excel[120] data extraction form was used to extract the following details from each study: first author, year of publication, study design, setting, population, disease, outbreak phase, sample size, intervention, comparator, stigma measure, and outcomes. All extracted data were verified by a second reviewer.

Risk of bias was assessed using the revised Cochrane risk of bias tool for randomised trials (RoB 2),[233] the Risk Of Bias In Non-randomized Studies - of Intervention, Version 2 (ROBINS-I V2),[234] and the Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist[235] as relevant. Quantitative evidence for each intervention was then critically appraised using the Grading of Recommendations Assessment, Development, and Evaluation (GRADE)[236] framework, while qualitative evidence was assessed using the GRADE Confidence in the Evidence from Reviews of Qualitative research (CERQual) framework.[237]

5.3.4 Additional literature sources

To supplement the systematic review findings, indirect evidence was considered from non-outbreak infectious disease contexts such as HIV, tuberculosis, and leprosy. Relevant reviews were identified by tagging during the systematic review screening, manually checking reference lists, searching PROSPERO for completed reviews, and inviting contributing experts to suggest additional sources. Meta-reviews were prioritised, and individual reviews already included within these were excluded to avoid duplication. The quality of included reviews was appraised using the Assessing the Methodological Quality of Systematic Reviews version 2 checklist.[238]

Qualitative or observational studies that did not evaluate a specific intervention but offered insights relevant to stigma reduction strategies (e.g. acceptability surveys) were also considered separately.

A focused grey literature search was conducted in parallel to identify practical guidance and reports on stigma reduction in outbreak contexts. This included site-specific queries on WHO, IFRC, UNICEF, Médecins Sans Frontières, Save the Children, and Social Science in Humanitarian Action Platform websites, as well as community organisation websites. Reference lists were also screened. Grey literature was reviewed independently at this stage, rather than integrated into the systematic review, as the review's eligibility criteria required studies to be externally peer-reviewed for quality purposes.

5.3.5 Stakeholder and affected community suggestions

Findings from the preceding chapters also informed the guidelines. International stakeholder suggestions for stigma reduction were identified from Chapter 3 (Table 3.6), while community preferences for interventions across Ebola disease, mpox, and Nipah virus disease were drawn from the results of the Stigma-SCANR stigma reduction module in Chapter 4 (Table 4.6) (see Box 5.1 regarding terminology).

Box 5.1: Limitations of contributor classification used in this chapter

The terms *stakeholders*, *affected communities*, and *experts* are used in this chapter to distinguish the different research processes that contributed to guideline development. This classification is for methodological clarity rather than a true separation. It is recognised that affected communities also provide expertise through lived experience, and individuals from these communities were also represented within the stakeholder and expert groups.

5.3.6 Evidence synthesis

The above sources were synthesised to generate draft guidelines in four steps:

Step 1: Identification and classification

All proposed measures identified across the evidence base were extracted into a Microsoft Excel sheet.[120] These included a heterogeneous mix of suggestions.

Distinguishing between the different origins of proposed actions is a recognised challenge in guideline development.[239] In previous WHO guideline processes, absence of this distinction has been noted to result in strong recommendations that seem discordant with their very low certainty evidence.[239] To avoid this, a typology recently proposed by Norris[240] was applied to classify each proposal broadly as either:

- A **guiding principle** and corresponding good practice indicator: a value- or rights-based consideration or associated practice proposed to prevent outbreak response organisations contributing to stigma, or
- A **recommended intervention**: a specific, evidence-informed action that can be implemented during a particular outbreak phase to actively mitigate stigma.

Where necessary, elements of suggestions were included in both groups.

Step 2: Organisation into framework

The four themes derived inductively from the stigma reduction component of the stakeholder interviews in Chapter 3 (i.e. knowledge exchange, policy and service design, psychosocial support, and community involvement and advocacy) were used to group proposed guiding principles and good practice indicators.

Recommended interventions were grouped according to the phase of the outbreak in which they were considered most relevant or actionable (i.e. preparedness, response, or recovery).

Step 3: Drafting and refinement

Good practice indicators were linked to guiding principles, with additional indicators and principles added where necessary. The rationale for each guiding principle was stated, drawing on human rights and ethical frameworks.

Each recommended intervention was accompanied by implementation notes (including examples), types of stigma addressed, and a summary of the supporting evidence.

All content was refined in an iterative process by the working group (consisting of my supervisory team, the three research assistants, and myself).

Step 4: Application of the WHO-INTEGRATE framework

Each recommended intervention was appraised using the WHO-INTEGRATE evidence-to-decision framework.[241] The criteria include considerations of the balance of health benefits and harms, human rights and sociocultural acceptability, health equity, societal implications, financial considerations, feasibility, and quality of evidence. The sub-criteria applied, and the main evidence sources for each, are detailed in Appendix D.3.

5.3.7 Expert identification

An expression of interest for expert consultation was distributed via ISARIC, PSI, and GOARN networks. Thirty experts were purposively selected by the working group to ensure balanced representation across regions and disciplines, with attention to gender representation and priority given to those with direct experience in outbreak-related stigma reduction initiatives.

5.3.8 Expert consultation

The selected experts pre-reviewed the draft principles and interventions, along with their evidence profiles, and provided initial comments. They also completed a survey rating their agreement with the inclusion of each guiding principle on a four-point Likert scale (strongly agree to strongly disagree), based on the following criteria adapted from Guyatt et al.[239]:

- Is the message really necessary?
- Is the message clear, actionable, and achievable?
- Is the net benefit large and unequivocal?
- Is the evidence difficult to collect and summarise?
- Are there specific issues that should be considered (e.g. equity)?
- Is the rationale explicit and sound?
- Is the evidence better formally assessed?

An optional open-ended question invited feedback at the end of each guiding principle.

Each expert attended one of five three-hour sessions to discuss guideline revisions and the nature and strength of recommendations. Each session focused in-depth on a subset of guiding principles and recommended interventions, with a brief review of the rest of the guideline content (example of meeting slides in Appendix D.4). Meetings were recorded and minutes were taken and reconciled by the co-chairs (CZZ, RS, MG) and myself. The consensus processes for guiding principles and interventions are detailed in Figures 5.2 and 5.3 respectively.

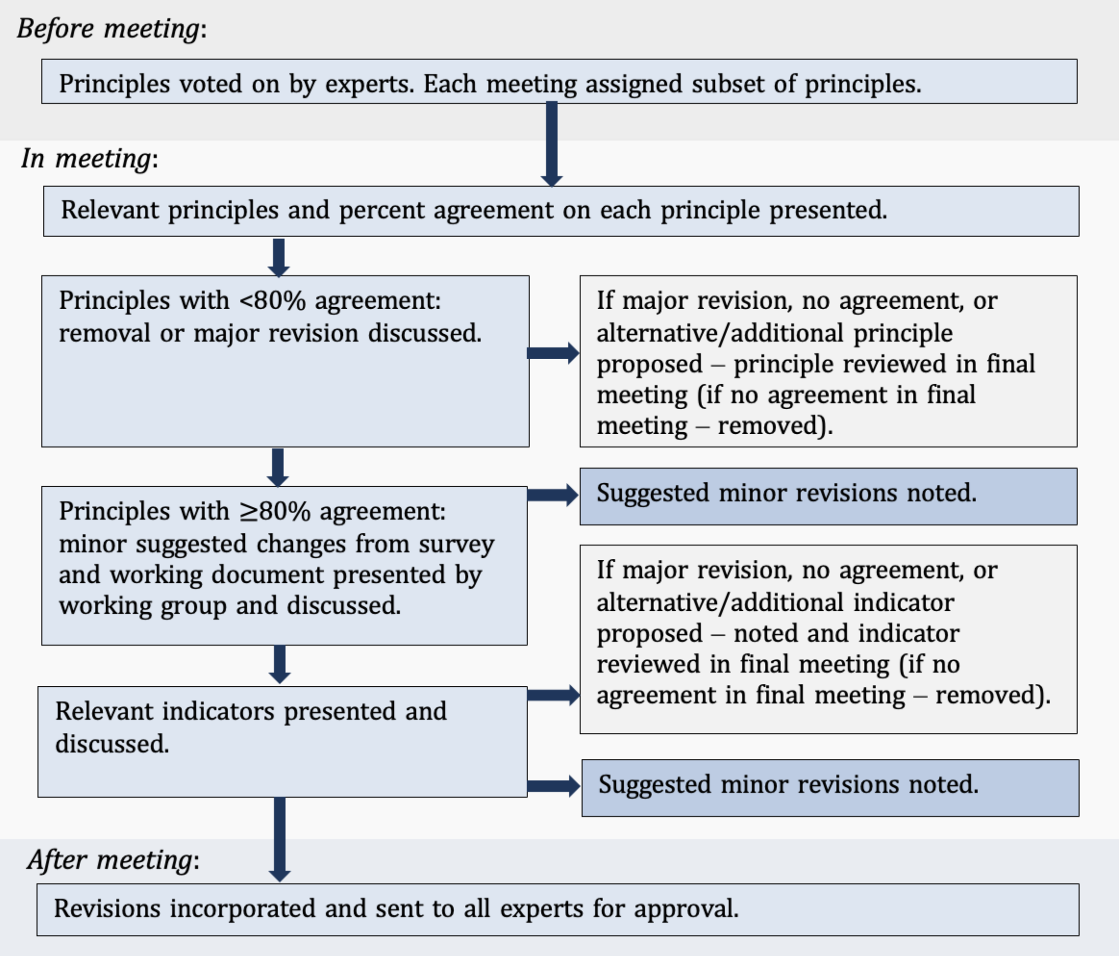


Figure 5.2: Consensus process for guiding principles

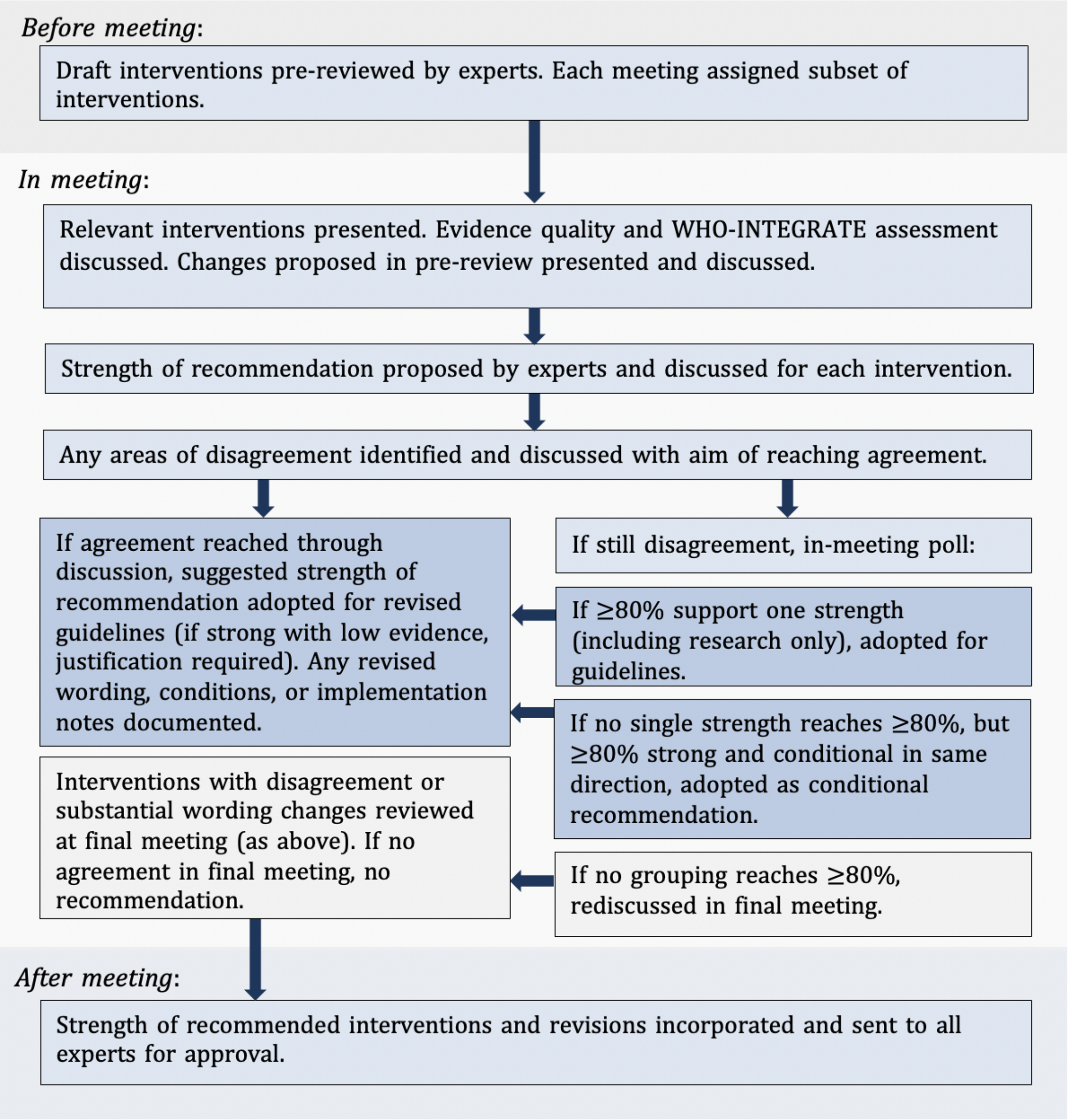


Figure 5.3: Consensus process for recommended interventions

Although strong recommendations are usually based on moderate or high certainty evidence, the WHO handbook for guideline development outlines five situations in which a strong recommendation may still be justified despite low or very low certainty evidence.[232] This list was shared with the expert panel, and when a strong recommendation was proposed despite a weak evidence base, experts were asked to justify this with reference to the list. This rationale was documented alongside the recommendation.

5.4 Results

5.4.1 Evidence base and expert characteristics

Systematic review results

The systematic review yielded 11 eligible studies from 4,163 unique results (Appendix D.5). These studies were conducted between 2008 and 2024 across seven countries and included randomised controlled trials (n = 7) and qualitative studies (n = 4). Interventions focused on stigma associated with COVID-19 (n = 6), Ebola disease (n=2), mpox (n = 1), SARS (n = 1) and a hypothetical infectious disease (n = 1); across response (n = 7) and recovery (n=4) outbreak phases. Risk of bias assessment classified most RCTs (n = 5) as having "some concerns", with one assessed as high risk of bias, and one as low risk. All qualitative studies (n = 4) were considered "mostly methodologically sound" (Appendix D.6).

Additional literature

Fifteen indirectly relevant systematic reviews were identified, two of which were meta-reviews (Appendix D.7). Seven non-interventional primary studies were identified as supporting data (Appendix D.8). The targeted grey literature search produced 27 documents related to stigma reduction from 714 results. However, none of these documents included formal evaluation of stigma reduction interventions. They were therefore reviewed by the working group for background context but not included in the evidence base.

Expert panel characteristics

One hundred and nineteen experts submitted expressions of interest for the expert panel. Five experts were selected from each WHO region with expertise across all pre-identified pathogen groups and outbreak response roles (Table 5.1).

Table 5.1: Guideline development expert panel characteristics

Expert characteristics	**No. experts (%); N=30**
Gender identity	
Man	16 (53)
Woman	13 (43)
Non-binary	1 (3)
Pathogen-specific expertise	
Coronaviruses (e.g. SARS-CoV-2)	30 (100)
Orthomyxoviruses (e.g. Influenza A virus)	16 (53)
Flaviviruses (e.g. Dengue virus)	11 (37)
Poxviruses (e.g. Monkeypox virus)	11 (37)
Paramyxoviruses (e.g. Nipah virus)	11 (37)
Vibrionaceae (e.g. *Vibrio cholerae*)	9 (30)
Filoviruses (e.g. Ebola virus)	9 (30)
Arenaviruses (e.g. Lassa virus)	3 (10)
Corynebacteriaceae (e.g. *Corynebacterium diphtheriae*)	2 (7)
Bunyaviruses (e.g. Oropouche virus)	2 (7)
Nairoviruses (e.g. Crimean-Congo haemorrhagic fever virus)	2 (7)
Togaviruses (e.g. Chikungunya virus)	1 (3)
Enterobacteriaceae (e.g. *Salmonella enterica*)	1 (3)
Roles in outbreak	
Risk communication and community engagement	22 (73)
Social science research	16 (53)
Personal lived experience	15 (50)

Continued on next page

Table 5.1 – continued from previous page

Expert characteristics	No. experts (%); N=30
National policymaking	14 (47)
Clinical response	11 (37)
Patient advocacy	9 (30)
Clinical research	9 (30)
Psychosocial support	7 (23)
International policymaking	6 (20)
Surveillance	2 (6)

Experts could select more than one pathogen and role. Three selected experts were unable to consistently participate in all expert panel activities (WHO region: Eastern Mediterranean, South-East Asian, African; Gender: two men, one woman).

5.4.2 Anti-stigma guiding principles

The final ISARIC Anti-Stigma Guidelines include nine guiding principles grouped into three themes:

- Communication and knowledge exchange
- Policy and governance
- Service design and delivery

The expert panel elected to integrate the initial fourth theme (community involvement and advocacy) throughout the guidelines rather than keeping it as a separate subsection.

The guiding principles and associated good practice indicators are presented in checklist format to support practical use (Table 5.2). The rationale for each principle, along with related rights and ethical considerations, is provided in Appendix D.9.

Table 5.2: Anti-stigma guiding principles checklist

Guiding principles	Good practice indicators (In practice, this means. . .)
Communication and knowledge exchange:	
1. All health communication should reflect the humanity and dignity of affected populations.	☐ Criminalising or violent metaphors are not used (e.g. people are not referred to as “suspects”, war on disease analogies are avoided). ☐ Individuals are not reduced to their disease status in public communications (e.g. people are not referred to as “carriers” or “superspreaders”). ☐ Fear-based portrayals are not used (e.g. imagery does not only focus on the most severe or terminal stages of the illness). ☐ Public and internal communications about the outbreak centre the lived experience of those affected, including recovery stories.
2. Messaging should not imply that specific groups are responsible for the outbreak.	☐ Media reflects the diversity of affected populations. ☐ Communications explain transmission-based risk (both how the disease is and is not transmitted) rather than implying risk based on identity. ☐ Messaging does not imply moral failure or irresponsibility (e.g. overemphasising preventability through personal hygiene). ☐ Disease names that reference places, animals, or groups of people are avoided and/or challenged. ☐ Public communications promote social cohesion and solidarity and counter misinformation that may further ‘us versus them’ social divisions.
3. Outbreak communication mechanisms should be designed for two-way engagement with communities.	☐ Mechanisms exist for community feedback, questions, and knowledge sharing. ☐ Social listening channels are maintained and reviewed with communities. ☐ Public health communications are co-designed with affected groups. ☐ Systems are in place to adapt communication based on community feedback and emerging concerns.

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Table 5.2 – continued from previous page

Policy and governance:	
4. Affected communities should be meaningfully involved in decisions that impact them.	☐ Diverse affected community members/groups are included in decision-making structures and empowered to shape outbreak response. ☐ The perspectives of groups facing unique risks (e.g. youth, incarcerated people) are sought and incorporated into response efforts. ☐ Rapid community engagement mechanisms exist for time-sensitive decisions. ☐ The scope and limitations of engagement processes are transparently communicated. ☐ Community engagement initiatives allow for low-profile or anonymous involvement. ☐ Community collaborators are offered financial and/or training support to enable meaningful engagement. ☐ Structures are in place to support community-led interventions.
5. Outbreak response institutions should model the inclusive and transparent behaviours they promote.	☐ Transparent, inclusive hiring practices are in place, with explicit consideration of intersecting forms of marginalisation. ☐ Confidential whistleblowing and discrimination reporting systems are accessible and have clear escalation pathways. ☐ Institutional policies and procedures are actively reviewed to identify stigma risks and adapted in response to risks identified. ☐ All staff are trained in non-stigmatising care practices. ☐ Pay structures are transparent and equitable, with consideration for the local context and level of risk.
6. The effectiveness and adverse effects of outbreak control measures and stigma reduction interventions should be assessed and transparently reported.	☐ Adverse psychosocial effects of outbreak control interventions are monitored, formally reported, and used to inform practices going forward. ☐ Evaluation strategies are in place for stigma reduction interventions and the outcomes are formally evaluated and documented. ☐ Reporting includes a clear description of the extent and nature of community engagement. ☐ Community members involved in research or response efforts are appropriately credited according to their preferences.

Continued on next page

Table 5.2 – continued from previous page

Service design and delivery:	
7. Outbreak services should be designed to minimise dehumanisation and alienation.	☐ Othering imagery and terminology are avoided in labelling facilities and procedures (e.g. naming facilities “treatment centres” instead of “isolation units”). ☐ Facilities and procedures are designed to protect privacy and avoid inadvertent disclosure (e.g. not using disease-labelled vehicles or separate health facility entrances). ☐ Facilities and services are accessible to those facing intersecting marginalisation (including people who are displaced). ☐ Personal belongings are handled respectfully, only removed when necessary, and returned when possible.
8. Outbreak measures are evidence-based and no more restrictive than necessary to minimise social disruption.	☐ Interventions, guidelines, and procedures are aligned with best available evidence, including social and behavioural science. ☐ Transmission based precautions, such as personal protective equipment use, reflect the latest evidence on infection risk and transmission. ☐ Facilities and standard operating procedures are designed and adapted to optimise safe contact between people receiving care and loved ones (e.g. facilitated digital contact, proportionate visitor restrictions). ☐ Interventions such as isolation and treatment take place within communities as far as possible. ☐ Financial and material losses are minimised and adequately compensated for. ☐ Families are given the opportunity to confirm the identity of a body prior to burial and perform safe closure practices.
9. Psychosocial support should be accessible to affected populations and frontline workers as part of outbreak management.	☐ Outbreak planning and management includes psychosocial support for community members directly and indirectly affected by the outbreak. ☐ Frontline workers have access to psychosocial support. ☐ Funding for psychosocial support is included in response and recovery budgets. ☐ Support allocation takes into account non-medical impacts of the outbreak such as income loss, grief, and caregiving needs, with sensitivity to gender disparities in distribution of caregiving responsibilities.

5.4.3 Recommended stigma reduction interventions

The final recommended stigma reduction interventions detail 18 evidence-based, expert-endorsed activities that organisations could introduce at each phase of an outbreak (Figure 5.4). Implementation suggestions, a summary of the evidence, WHO-INTEGRATE considerations, and the overall certainty of the evidence for each intervention are detailed in Appendix D.10.

The term "recommended interventions" indicates endorsement by the expert panel, while recognising that not all actors will have the mandate or capacity to implement all of them. In line with the WHO guideline development handbook, strong recommendations use the phrasing "we recommend", while conditional recommendations use "we suggest".[232]

Preparedness

A1	↑↑	We **recommend** providing stigma-sensitive training to service providers who interact with affected individuals, including providers outside health settings.	🧑‍⚕️
A2	↑↑	We **recommend** including stigma awareness as a component of health education initiatives for children and adolescents, particularly when an outbreak may affect these age groups.	👫
A3	↑↑	We **recommend** pre-designing psychosocial support interventions that can be delivered under strict infection control measures.	🗣 👫
A4	↑	We **suggest** facilitating community dialogues about relevant infectious diseases and stigma in outbreak-prone areas as part of outbreak preparedness.	👫
A5	↑	We **suggest** incorporating person-centred features into personal protective equipment design and protocols to minimise depersonalisation.	🧑‍⚕️ 🏢
A6	↑	We **suggest** collaborating on preparedness activities with community members affected by previous outbreaks or illnesses with transferable learnings.	👫 🏢

Response

B1	↑↑	We **recommend** embedding stigma reduction messages in public health education and risk communication efforts.	👫 🏢
B2	↑↑	We **recommend** facilitating public engagement with affected individuals’ experiences.	👫 🧑‍⚕️
B3	↑↑	We **recommend** offering accessible psychosocial support and resources to those affected by the outbreak, such as remote services during isolation.	🗣 👫
B4	↑↑	We **recommend** co-designing, adapting, and implementing stigma awareness initiatives for the local context with affected community members, including people with lived experience of the illness.	👫 🏢
B5	↑	We **suggest** facilitating peer support opportunities led by people with lived experience.	🗣 👫

B6	↓	We **suggest *against*** introducing community protection bylaws that impose fines for stigmatisation of affected persons.	👥 🏢
B7	📚	We support **further research** on the stigma impact, feasibility and acceptability of community-based quarantine, isolation, and care.	👥 🏢

Recovery

C1	↑	We **suggest** implementing initiatives that help people who have recovered reintegrate into their households, workplaces, schools, religious practices, and other community activities.	🧑‍⚕️ 👥 🏢
C2	↑	We **suggest** including assessment of psychosocial wellbeing as part of integrated follow-up care for people who have recovered and offering referral to longer-term support services.	🗣 👥
C3	↑	We **suggest** documenting, robustly evaluating, and publishing stigma reduction efforts.	🧑‍⚕️ 🗣 👥 🏢
C4	📚	We support **further research** on the effectiveness, acceptability, and potential harms of facilitating visible contact between response workers and recovered persons.	🗣 👥
C5	📚	We support **further research** on the effectiveness, acceptability, and potential harms of recovery celebrations.	👥 🏢

Strength of recommendations:

↑↑	**Strong recommendation in favour**
↑	**Conditional recommendation in favour**
📚	**Support for use in further research only**
↓	**Conditional recommendation against**
↓↓	**Strong recommendation against**

Stigma types:

👥	**Social stigma**
🧑‍⚕️	**Provider/authority-related stigma**
🏢	**Structural stigma**
🗣	**Self stigma**

Figure 5.4: Overview of recommended interventions

5.5 Discussion

5.5.1 Contextualisation and applications of the guidelines

This chapter presents the ISARIC Anti-Stigma Guidelines as evidence-based consensus guidance for mitigating outbreak-related stigma. By framing stigma reduction as a series of actionable steps rather than an abstract concern, the guidelines translate a longstanding but often neglected challenge into concrete measures that can be applied across outbreaks.

This work extends previous outbreak-related stigma guidance through the integration of current evidence, affected community perspectives, and expert consultation. The guidelines corroborate several recommendations made by Fischer et al.[82] and Gronholm et al.[225] based on reviews that predated the COVID-19 literature. However, both of these studies were grounded in findings from non-outbreak contexts, resulting in important differences. For instance, both studies emphasised running "anti-stigma campaigns", which is a common strategy for HIV and mental health stigma. In contrast, in the development of the ISARIC Guidelines, such suggestions were met with concerns about information fatigue, conflicting messaging, and optimising resource allocation. Embedding stigma reduction messaging into existing health education initiatives (*Intervention A2*) and risk communication (*Intervention B1*) is therefore recommended instead.

The Anti-Stigma Guidelines are specifically designed for outbreak response organisations, including public health agencies, ministries of health, civil society organisations, healthcare services, and research institutions. These organisations have both an ethical and operational interest in mitigating stigma, and are well positioned to do so. In practice, however, the competing priorities of outbreak response necessitate clear and structured guidance to ensure this responsibility is met.

The checklist of guiding principles and good practice indicators is designed for periodic use by these organisations to ensure policies, communications, and interventions do not exacerbate stigma. Depending on organisational structure, each section may need to be reviewed by different team members (e.g. indicators related to hiring practices could be assigned to human resources teams). However, the checklist emphasises that stigma is an organisation-wide issue that warrants attention across domains such as policy and service design. This contrasts with earlier guidance that typically placed primary responsibility for stigma reduction within risk communication and community engagement.

Each recommended intervention is accompanied by icons indicating the types of stigma it addresses. These are intentionally aligned with the structure of the RAPID Stigma Scales described in Chapter 4 to provide a direct link between stigma assessment and recommended actions.

The guidelines encourage adoption of multiple interventions in combination where feasible. This is supported by evidence of a dose–response in HIV stigma research, where participants exposed to multiple stigma reduction interventions showed greater reductions in stigmatising attitudes compared to participants only exposed to one intervention.[242]

5.5.2 Opportunities for effectively mitigating stigma

Together, the guidelines indicate that there are a wide range of practical opportunities for addressing stigma within outbreak preparedness, response, and recovery. Opportunities judged to hold particular promise are briefly discussed below.

A recurring emphasis of the guidelines is the need to expand avenues for community involvement and leadership, both in stigma interventions and in outbreak response more broadly. In the guiding principles (e.g. *Principle 4*), this reflects the ethical concept of "nothing about us without us",[243] while in the recommended interventions (e.g. *Intervention B4*), it points to the enhanced effectiveness of community-led, context-sensitive approaches. This focus on community involvement also extends to preparedness, where involving previously affected communities is recommended (*Intervention A6*).

Although the terminology of 'social contact' interventions used in the broader stigma literature may be less suited to outbreaks, the findings demonstrate that the underlying principle remains relevant (*Intervention B2*). Safe opportunities for interaction with those affected through digital platforms or the involvement of recovered individuals in community engagement efforts can reduce perceived divisions between affected groups and the wider public, mitigating a precondition of stigma.[227,244] These approaches align with wider evidence that communities with strong social bonds are better able to withstand and recover from crises.[64]

As mentioned above, embedding anti-stigma messaging into risk communication (*Intervention B1*) is another promising intervention with support from stakeholders and two RCTs.[244,245] This is aligned with wider health communication literature, which emphasises that factual information provision in isolation is insufficient to shift deeply rooted attitudes and fears.[29,246] In contemporary outbreak settings, where misinformation spreads rapidly through social media channels, there is a particular need for stigma-sensitive messaging delivered by trusted sources.[247] However, framing matters: poorly designed communications may inadvertently reinforce stereotypes or fear, further entrenching stigma (*Principle 1 and 2*).[248,249]

In terms of self stigma, brief online psychosocial interventions have demonstrated effectiveness for reduction in the short term (*Intervention A3 and B3*).[250,251] Similar approaches in HIV and mental health, including peer-led counselling and cognitive reframing, have shown comparable effects.[252,253] Increased online engagement, accelerated by the COVID-19 pandemic, has made such approaches more widely feasible. However, applicability is still variable across settings and repeated delivery may be necessary to sustain effects.[254]

The guidelines also recommend against actions such as the use of disease names that are associated with specific groups of people, war analogies, unnecessary destruction of property, and the introduction of punitive community bylaws. These ‘what not to do’ measures are often the low-hanging fruit in terms of stigma mitigation. Despite this, they frequently remain unaddressed. For instance, disease names such as “Sudan virus disease” remain in use in spite of repeated recognition that geographical disease labels should be avoided, including during a 2019 filovirus renaming effort.[255]

The guideline recommendations not only address different outbreak phases and stigma types, they also intervene at different stages of the stigma process. This is evident when mapped onto the Hourglass Stigma Model from Chapter 3 (Figure 5.5).

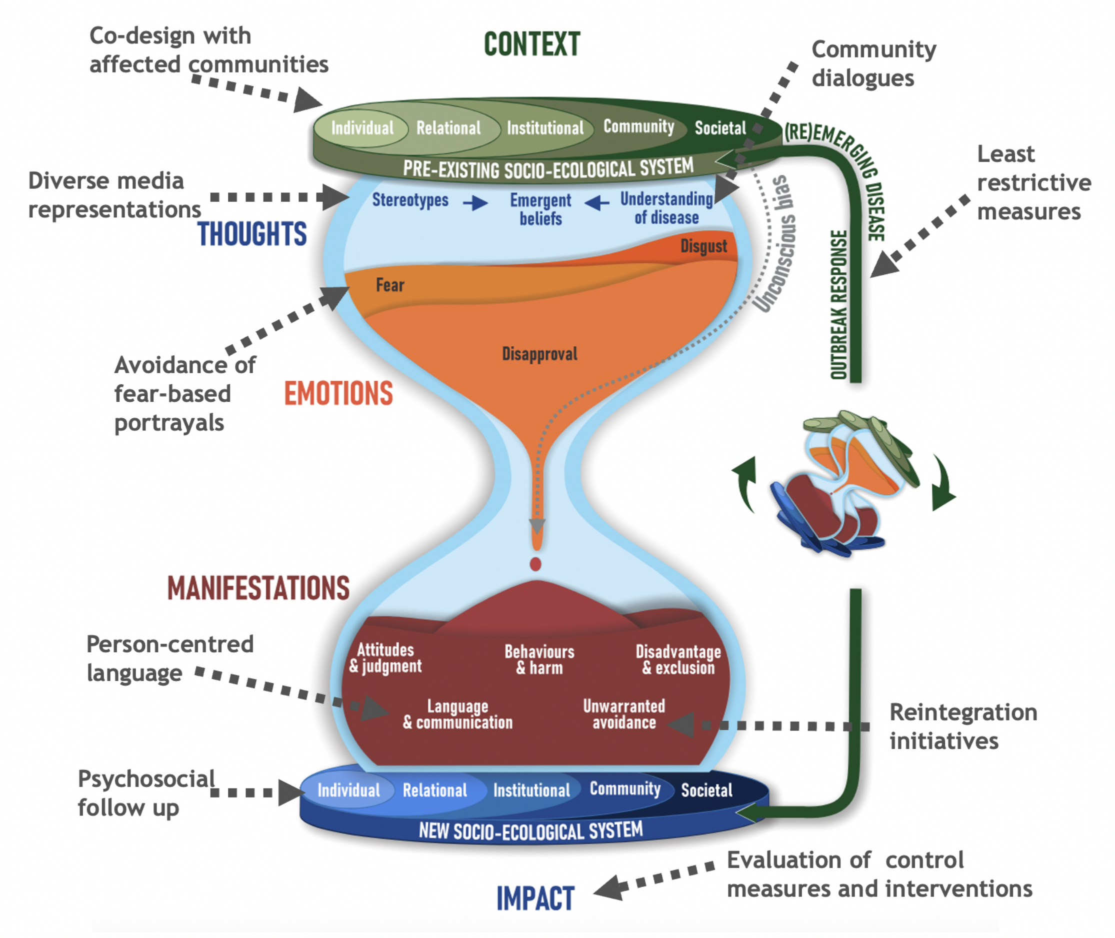

Figure 5.5: Examples of intervention points in relation to the Hourglass Stigma Model

5.5.3 Challenges encountered during guideline development

A key challenge in developing these guidelines was achieving a balance between specificity and flexibility. This is a common tension in international guideline development.[256] Recommendations must be detailed enough to guide practice, but sufficiently generalised to remain applicable across diverse contexts. For instance, to allow for flexibility, the expert panel chose not to specify the mode of delivery for interventions (e.g. in-person versus online psychosocial support), with implementation notes detailing possible approaches instead. While this allows for broader applicability, it also risks making the recommendations appear vague and therefore less readily implementable.

A similar tension emerged in keeping the guidelines brief while also providing the explanation warranted to specify caveats and unpack complexity. To balance these considerations, short summaries (as presented in the results section) were prepared alongside the full guidelines.

Another challenge was the scarcity of direct evidence available to inform guideline development. This likely stems from the urgency and resource constraints of outbreak settings, compounded by the inherent complexity of evaluating social and behavioural interventions.[257] While indirect evidence helped to broaden the evidence base, it was limited by the heterogeneity of outcome measures, which meant findings were often descriptive and non-specific.

Lastly, even in the absence of conflicts of interest, each working group member and expert inevitably entered the consensus process with their own priorities and preferred vocabulary. Reconciling these differences highlighted the need for compromise in producing guidance across disciplines and contexts. For example, there were conflicting views on terminology such as "psychological support" versus "mental health support", and differing preferences regarding using established terminology in the field (e.g. intersecting marginalisation) versus plain language.

5.5.4 Strengths and limitations

The main strength of this chapter is its integration of diverse forms of evidence, including direct, indirect, and experiential sources, to produce an actionable set of anti-stigma guidelines. This included incorporating stakeholder perspectives and suggestions from affected communities, which has been shown to enhance the uptake and relevance of guidelines in practice.[258] It also involved input from a diverse international expert panel, enhancing the transferability of the guidelines across contexts. The alignment with outputs from earlier chapters, particularly the

RAPID Stigma Scales, is a further strength, as this allows for continuity between stigma assessment and reduction. Use of structured appraisal frameworks (GRADE, CERQual, WHO-INTEGRATE) ensured transparent consideration of the certainty, acceptability, feasibility, and equity of proposed interventions.

Several limitations should also be noted. The systematic review only included interventions explicitly designed to reduce stigma. Interventions that influenced stigma indirectly may therefore have been missed. Dividing the expert consultation process across multiple meetings enabled detailed discussion but meant each expert only provided in-depth feedback on a subset of the guidelines. The use of expert meetings, rather than more anonymous consensus processes, also heightened the influence of power dynamics and linguistic differences, which may have affected which views were expressed and incorporated. Additional opportunities for individual written feedback from experts on all guidelines were provided to account for these limitations. Finally, although informed by the WHO handbook, the resulting guidelines are not WHO-endorsed or externally reviewed, and the handbook has been noted to be more suited to developing clinical rather than equity-oriented recommendations.[259,260]

5.5.5 Future research

Increased reporting of stigma reduction efforts is needed to avoid the recurrent loss of operational learning that has characterised past outbreak responses.[261] Without this documentation, opportunities to understand effectiveness and improve practice will continue to be missed.

More robust research evaluation methods are also needed, with the field lending itself to mixed methods evaluation and pragmatic trials.[262] Establishing effect sizes would be useful for allocating resources. For example, a meta-analysis of 79 studies on mental health stigma (representing over 38,000 research participants) found that interventions based on social interaction were more effective than those based on education for adults, with the opposite true for adolescents.[263] In contrast, HIV stigma reduction data suggest comparable effects (possibly because prevailing stereotypes are less readily disprovable).[264] This has informed intervention design and resource prioritisation for each of these contexts.[264] More data are required to do the same in outbreak contexts. Long-term follow-up should also be incorporated to determine the duration of intervention effects, and implementation studies are needed to understand the feasibility, cost, and scalability of proposed interventions.

At the same time, the guidelines' structure emphasises that a distinction is needed between measures that warrant evidence and those that should be implemented on principle. For example, scholars have previously suggested that because there is no evidence of a reduction in stigma following previous renaming efforts, it is unlikely that "changing the labels of conditions will reduce the stigma associated with those conditions in any major way."[265] This overlooks both the variable origins of stigma (as detailed in Chapter 3), and the *ethical imperative* to avoid stigmatising disease names. With limited resources for outbreak-related social research, evaluating measures that will remain important as a matter of principle is unlikely to be a productive avenue of enquiry.

Rather than fixed solutions, the guidelines presented in this chapter are intended as a practical starting point for addressing outbreak-related stigma. As the evidence base grows, guidance will need to be updated. The guidelines could offer a foundation for the development of disease or context-specific recommendations, as has been done for HIV anti-stigma guidance.[266]

5.5.6 Conclusions

This chapter brings together available evidence, affected community perspectives, and expert input to produce the ISARIC Anti-Stigma Guidelines. These provide guiding principles and recommended interventions to support stigma-sensitive decision-making across outbreaks.

6

Concluding remarks

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6.1 Chapter preface

The Virulence of Otherness

It's a story as old as the tide;
the virus multiplies but we divide:
those with safe pockets, those with hands pressed;
ventilators for a few, soap and prayers for the rest.
The "them" they say started it, the "we" who are saviors;
nationalism against need, foreigners from neighbors.
In the epoch of empathy does solidarity sit spoiled?
We raise not our gaze from where we lie coiled.
"The viruses must have a common origin," we say
forgetting that we did too, back in the day.

Originally published as
Paterson A. The Virulence of Otherness.
Annals of Internal Medicine, 2024

6.2 Overview of key findings and outputs

The impact of an infectious disease outbreak is determined not only by the pathogen involved, but also by the social responses it provokes. Stigma is among the most consistent of these responses. Although it repeatedly worsens suffering, deepens inequities, and impedes disease control, outbreak-related stigma has rarely been approached in a structured way. This thesis aimed to address this by producing tools for conceptualising, assessing, and reducing outbreak-related stigma.

The key findings and outputs of each chapter are briefly outlined below.

- **Chapter 2** demonstrated that rigorous stigma scale development and validation during outbreaks is difficult. Conventional approaches were noted to produce tools of limited validity, which were typically published too late to inform outbreak response, and seldom reused. Similarities in the content of scales highlighted the opportunity for more cross-cutting and pre-emptive approaches.
- **Chapter 3** detailed the multiple drivers of outbreak-related stigma and the breadth and depth of its impacts. Stakeholder expertise across multiple outbreak settings were synthesised into the Hourglass Model, as a structured framework for considering how stigma emerges and manifests in outbreaks.
- **Chapter 4** introduced the RAPID Scales and Stigma-SCANR as the first validated cross-outbreak stigma assessment tools. The tools' strong psychometric performance in field-testing with communities affected by Ebola disease, mpox, and Nipah virus disease demonstrated their ability to assess stigma with fidelity across outbreaks.
- **Chapter 5** presented the ISARIC Anti-Stigma Guidelines, composed of nine guiding principles and 18 recommended interventions. These set out consensus-

and evidence-informed approaches for mitigating stigma as part of outbreak preparedness, response, and recovery.

Overall, these findings demonstrate that although outbreak-related stigma is complex, it is amenable to structured review and reduction.

6.3 Contributions to the field

A common critique of the term stigma is that it is ‘under-defined and over-used’.[267] This thesis contributes to a deeper understanding of the definition and applications of stigma in the context of infectious disease outbreaks. Prior to this, conceptual work on health-related stigma has focused on non-communicable or non-outbreak disease contexts.[14,20,156,218] The thesis findings corroborate existing stigma theory by validating key conceptual distinctions in new settings. For example, they support the recognition of self stigma as a distinct construct arising from community stigma, as described in the mental health literature.[219] However, they also draw attention to outbreak-specific dynamics, such as the role of infection control practices in shaping stigma.

The empirical scope of this work is broader than existing disease-specific studies, but narrower than cross-cutting attempts to capture all forms of health-related stigma.[14,25,87,89] This positioning enables the outputs to contribute to the collective evidence base on cross-contextual stigma, while retaining the specificity needed to inform outbreak response. Findings such as the risk of inadvertent disclosure during follow-up procedures and the value of community-led interventions echo and expand on previous qualitative research.[195,217,227]

Operationally, this work advances the integration of stigma reduction into outbreak response by providing four new tools: the Hourglass Model, the RAPID Scales, the Stigma-SCANR, and the ISARIC Anti-Stigma Guidelines. Their development collectively involved engagement with close to 100 experts and stakeholders and testing with more than 1,000 affected community members. These tools support efforts to ensure that people affected by outbreaks can seek care without shame or fear of socioeconomic consequences. They mirror similar efforts in mental health,[59,113] HIV,[223,268] and leprosy.[19,269]

6.4 Future directions

The outputs of this work provide a coordinated approach to understanding and reducing outbreak-related stigma. The task ahead is to embed and expand these efforts within outbreak response systems. Three focus areas for future work follow.

6.4.1 Establishing stigma mitigation as a core operational priority

This thesis demonstrates that stigma can arise from and affect every pillar of outbreak response, with implications for infection prevention, clinical outcomes, and institutional trust. It therefore positions stigma as a key priority for outbreak control, in addition to being of social and psychological consequence. The practical implications of this are that stigma requires attention at the level of outbreak response leadership, and then mitigation across sectors, rather than being designated a risk communication and community engagement issue. While this requires additional leadership capacity and organisational adjustment, the recurrent harms of stigma to outbreak response should be galvanising. To support integration, the Hourglass Model offers response teams reflective prompts to identify inadvertent stigma risks early in preparedness or response, and the ISARIC Anti-Stigma Guidelines provide a checklist of good practice indicators for stigma-sensitive response.

Prioritisation also requires integration of stigma assessment into outbreak monitoring and reporting systems. The RAPID Stigma Scales and Stigma-SCANR provide a means of assessing stigma without the typical lag time of *de novo* development. These can be embedded in surveillance, community engagement, and evaluation activities. While approaches to implementation are expected to vary across organisations, the focus should consistently be on using the resulting data to inform stigma reduction. To facilitate this, stigma mitigation could be integrated into accountability frameworks, with clear goals and regular reporting, rather than being an implicit aspiration. Initiatives such as the WHO Outbreak Toolkit project, which equip outbreak field investigators with pre-defined and adaptable tools, are potential vehicles for integration.[270]

In addition, health system strengthening and response planning need to include strategies to address stigma, with social cohesion recognised as fundamental to community resilience. At a global governance level, the Pandemic Agreement and related World Health Assembly resolutions provide a supportive policy context for such strategies.[2–4] Reforms to the International Health Regulations could likewise explicitly commit to minimising stigma, given its harmful and far-reaching consequences. The resolution on public health and social measures has already been followed by implementation guidance.[271] This guidance offers flexible tools for monitoring social measures but focuses mainly on adverse economic impacts.[271] Future iterations could be strengthened by incorporating stigma considerations. At an operational level, preparedness simulation exercises should also include stigma-sensitive scenarios, and responder debriefing should provide space to reflect on stigma-related challenges or ongoing concerns.

6.4.2 Incorporating lived experience into governance

This work also demonstrates the value and feasibility of involving the people most affected by outbreaks in research and other aspects of response. Current practice often restricts the role of community contributors to superficial consultation, but meaningfully embedding lived experience in governance can reduce stigma risks and make response interventions more attuned to community realities. As highlighted in the ISARIC Anti-Stigma Guidelines, this offers the dual benefits of strengthening the equity and effectiveness of interventions.

People with lived experience of relevant conditions should be included in local outbreak decision-making bodies and national task forces, as well as in preparedness, response, and recovery efforts. For example, including lived experience in national Ebola preparedness efforts or Nipah virus disease follow-up programmes could strengthen attention to stigma within these processes. While training and support are required to make these roles sustainable, this investment helps ensure participation is meaningful for all parties rather than symbolic.

There is also scope to embed lived experience within global outbreak governance to support stigma-sensitive policymaking. For example, international advisory bodies, expert panels, and post-outbreak reviews could be mandated to include affected community representatives. This would enable their perspectives, rather than solely their biomedical data, to inform decision-making. The feasibility of these approaches has been established, with community representatives already playing a central role in HIV and mental health policymaking.[272,273] Recent policy developments signal growing recognition of lived experience more broadly. Brazil's Law 15.120/2025,[274] for instance, now mandates lived experience involvement in decisions about medications for the national health system.

6.4.3 Expanding the evidence base for stigma reduction

At present, there is a notable imbalance between efforts to document stigma and those to evaluate strategies for its reduction. This is evident in the discrepancy between the numerous stigma scale studies identified in Chapter 2 and the sparsity of interventional studies in Chapter 5. Without stronger evaluation, stigma research risks remaining descriptive rather than informing effective, evidence-based action. The key next step for stigma research will therefore be to move from recognition of the problem to generating robust evidence on reduction interventions.

The approaches most likely to generate this evidence include pragmatic trials, natural experiments, and mixed-methods implementation studies. These approaches should be seen as complementary and could be applied through grassroots initiatives, studies embedded within outbreak response, and international collaborations:

1. **Evaluation of grassroots initiatives:** Increased support for the implementation and evaluation of grassroots interventions is needed. The children's book described in Chapter 4 offers an example of this type of intervention, with evaluation currently in planning with Walimu and the Ministry of Health Uganda. On their own, these interventions can generate valuable, context-specific insights for stigma reduction. However, given the sporadic nature of outbreaks and need for cross-learning, the transferability of findings should also be considered. The use of robust and comparable evaluation methods will allow for synthesis of findings across settings. This could enable broader lessons to be drawn for future outbreaks, such as the conditions under which survivor interaction is more effective than public education.
2. **Embedding stigma research in outbreak response:** Another way to advance evaluation is to embed stigma research within outbreak response studies. This is a particularly sensible approach, since many activities with

potential to reduce stigma are not stand-alone interventions but adaptations of existing control measures. For example, survivors could be invited to co-lead risk communication and community engagement in particular communities, with stigma compared across sites. Embedding stigma evaluation into existing outbreak research could also reduce participant burden and optimise resources. However, achieving this will require interdisciplinary collaboration, advance planning, and flexible funding mechanisms.

3. **International collaborative efforts:** A further opportunity lies in conducting multi-country studies on outbreaks of regional or global concern. Such studies could generate evidence on how stigma reduction strategies perform across diverse contexts and at greater scale. With a 2–3% annual probability of a pandemic on the scale of COVID-19,[275] there is a strong case for starting to design such studies. International consortia may be best placed to coordinate these studies, in partnership with previously affected and at-risk communities. As emphasised in the ISARIC Anti-Stigma Guidelines, interventions need to be tailored to the local context, and study design will therefore need to allow for adaptation across sites. The priority should be to understand the circumstances under which different approaches are effective, rather than reducing evaluation to a binary assessment of whether an intervention works or not.

6.5 Project appraisal

6.5.1 Strengths

Several aspects strengthen the rigour and relevance of this work. First, the research spanned multiple outbreak contexts. This provided the rare opportunity to validate new tools across diverse geographical, cultural, and epidemiological settings. The involvement of stakeholders and experts from varied organisations, disciplines, and settings improved the transferability and future utility of outputs.[276] It also increased awareness and ownership of the research outputs among key actors in the field, thereby facilitating their uptake into practice.[258]

Second, the research design emphasised and incorporated lived experience. Community co-investigators were involved from conceptualisation, and people directly affected by outbreaks participated in stakeholder interviews and expert panel processes. This enhanced the contextual grounding and relevance of the findings, and supported inclusive knowledge generation.

Third, this work used a multi-method approach that combined systematic review, qualitative enquiry, quantitative psychometric validation, and structured consensus processes. This enabled triangulation of findings from different forms of evidence and perspectives, increasing the robustness of outputs.

Fourth, analyses incorporated structured appraisal frameworks such as COSMIN, GRADE, CERQual, and WHO-INTEGRATE. These ensured transparent assessment of evidence and enhanced the credibility of the findings and recommendations.

Finally, this research bridged theoretical and applied approaches to stigma. The development of the Hourglass Stigma Model, the RAPID Stigma Scales, and the Stigma-SCANR tool ensured that theory, measurement, and practice were linked, rather than treated in isolation.

6.5.2 Limitations

While limitations of individual methods are discussed in earlier chapters, there are also several overarching limitations.

This thesis takes a structured and relatively quantitative approach to stigma. This could be challenged by those who adopt an interpretivist paradigm, on the premise that stigma cannot be reduced to a set of Likert-scale items. Nonetheless, in time-pressured outbreaks, brief scales offer a practical means of capturing community-level sentiments. As a result, many researchers and public health practitioners will continue to seek to understand stigma through a quantitative lens. The validity of these approaches relies on the availability of robust tools.

The emphasis on tool development meant that detailed context-specific analyses were beyond the scope of this thesis. These analyses remain important for understanding how stigma manifests within particular social and cultural settings. Some of these analyses are already completed or underway, with the breadth of data generated through the Stigma-SCANR offering opportunity for further investigation.

The work also focuses on the negative construct of stigma rather than its positive counterparts, such as acceptance, solidarity, or forms of collective resilience.[218] This framing risks under-emphasising the salience of protective social processes. Greater attention to these links could enrich future stigma research. For example, the recent WHO Commission on Social Connection report[64] proposes developing a global Social Connection Index, which could be used alongside stigma assessment tools.

A further limitation relates to the constraints of adopting a public health approach to engage with a phenomenon as socially contingent and complex as outbreak-related stigma. Outbreak responses are shaped by multiple factors, including disease characteristics, funding availability, the actors involved, and underlying power relations. As a result, whether stigma is prioritised, and whether assessment tools or guidance are taken up, is influenced by socio-cultural and political considerations as much as by technical ones. There are also potential risks associated with the implementation of such tools, even when they are carefully designed and grounded in evidence and stakeholder input. Identifying stigma may have unintended effects, for example if it becomes a convenient explanation for broader response failures or a substitute for critical reflection on institutional practices. Similarly, tools intended to support learning may be reduced to procedural use rather than informing sensitive, context-specific action. These concerns highlight the importance of considering not only how tools are developed, but also how they may be used. The operational limits and risks described therefore remain important considerations for future efforts to address stigma in outbreak contexts.

Lastly, there are inherent limitations to my positionality. As an external researcher, I had privileged access to international experts and response organisations, but less direct access to affected community perspectives. My clinical background and the composition of the research team also meant that the impact of stigma on care provision and response operations was foregrounded, with less emphasis on impacts beyond health systems.

6.5.3 Challenges and reflections

Navigating collaborative research

The collaborative nature of this research made it both meaningful and challenging. First, while it enabled outputs to be shaped by end-users and those most affected, the process was not always well-suited to traditional research structures. For example, logistical requirements such as multi-country ethics review and pre-planned travel made it difficult to be responsive to emergent findings and priorities. This highlights the need for more flexible research mechanisms that accommodate iterative, participatory approaches, particularly in outbreak contexts where circumstances are rapidly evolving.

Second, during consensus processes, the size and diversity of panels generated heterogeneous feedback. This made maintaining the coherence of outputs more difficult. However, it also fostered more innovative and robust solutions to long-standing challenges in the field. This demonstrated that consensus can not only be achieved, but strengthened, by involving large and diverse panels. Additional observations were that panels tended to work within existing framing and were more likely to add, rather than reduce, items. A practical lesson for future processes is therefore that feedback is optimised when draft outputs are presented in a refined format, but with clear space for substantive suggested changes.

Third, the collaborative process meant that the final products inevitably looked different from what was originally envisaged by any individual contributor. For example, in the guideline development process I anticipated firmer statements on the integration of follow-up procedures into routine care. Framing the work as a shared endeavour helped create a collaborative environment where compromise was viewed as integral rather than as a concession.

Ensuring usability amid complexity

Balancing complexity and usability of outputs emerged as another central challenge throughout this research. Three forms of complexity were apparent: conceptual, methodological, and operational, each with the potential to undermine the adoption of outputs.

Conceptual complexity arose from the multidimensionality of stigma. Given the many different ways of conceptualising stigma, it was necessary, but difficult, to determine which dimensions to prioritise. It was initially considered important to capture harmful minority sentiments alongside majority views, to distinguish between actors and targets, and to include both anticipated and experienced stigma. However, incorporating these elements made tools such as the Stigma-SCANR relatively detailed, which risks reducing usability. Further prioritisation was therefore required to develop the RAPID Scales as a more concise option.

Methodological complexity stemmed from efforts to maintain rigour. Many of the methodological manuals and best practice guidelines used during this research exceeded 200 pages. I had the time to work through these, but recognise such time is rarely available to researchers in outbreak settings. This raised questions about how to communicate complexity without overburdening end-users. These considerations informed the development of one-page summaries of the Anti-Stigma Guidelines and the focus on actionable formats such as checklists.

Operational complexity due to the competing demands of outbreak response remains a challenge. Even when tools are conceptually sound and methodologically robust, their use depends on resources, priorities, and championing in the field. Ensuring the availability of tools is therefore only the first step. Looking ahead, adoption will require sustained commitment and resources, not only for application, but also for ongoing refinement as new evidence becomes available.

6.6 Conclusion

This thesis highlights that stigma is a recurrent and damaging feature of infectious disease outbreaks. It recommends pre-emptive consideration of stigma during outbreak preparedness, and active monitoring and mitigation during response and recovery. To support this, the thesis contributes a cross-outbreak conceptual model, validated stigma assessment tools, and evidence-based consensus guidelines on stigma reduction. Together, these provide a practical means for increasing sensitivity and responsiveness to the harms of stigma in future outbreak responses. This is critical for promoting the wellbeing of affected communities and improving outbreak control.

Appendices

A

Appendices for systematic review

Contents

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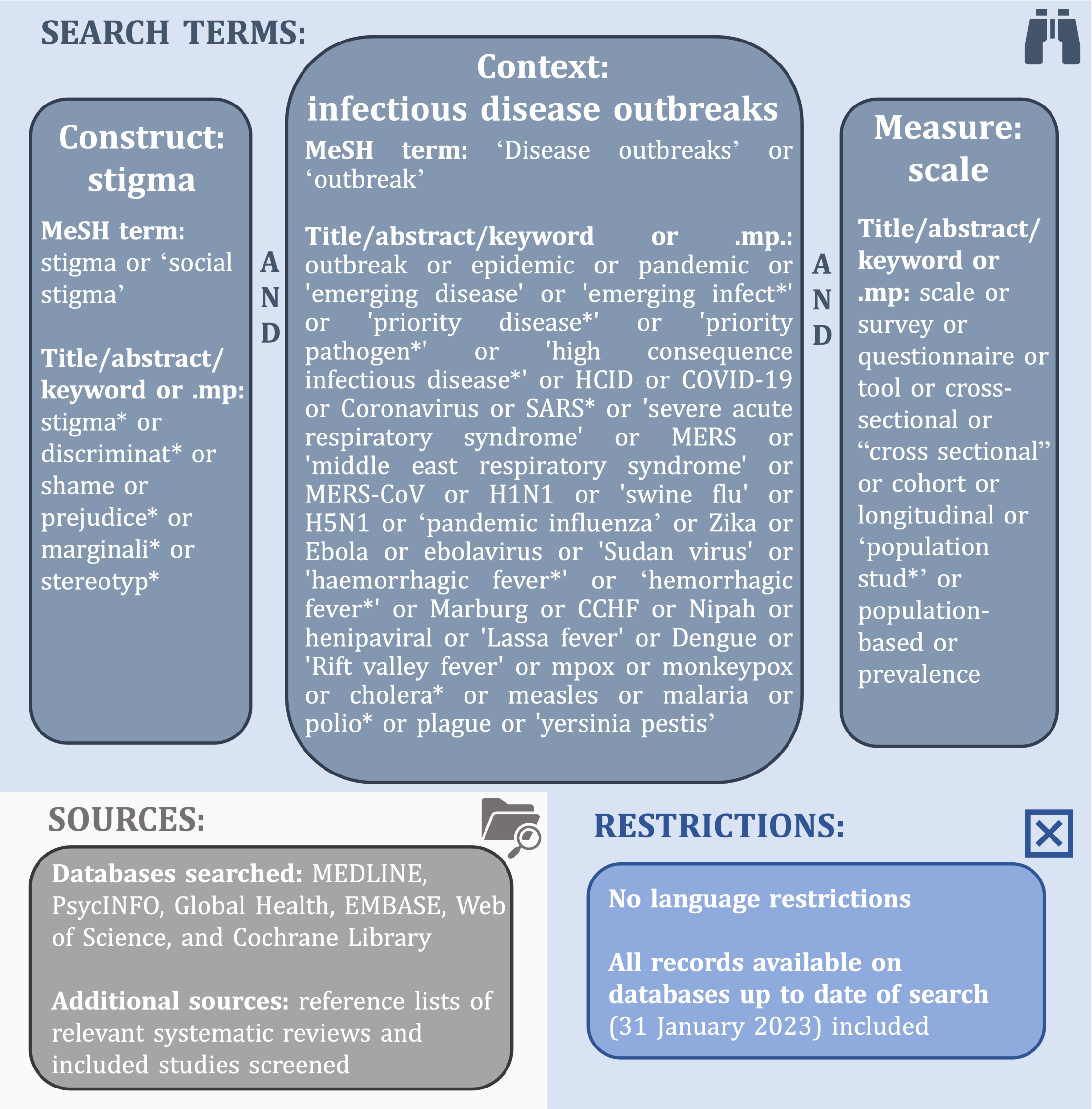
A.1 Details of search strategy



SEARCH TERMS:

Construct: stigma

MeSH term: stigma or ‘social stigma’

Title/abstract/keyword or .mp: stigma* or discriminat* or shame or prejudice* or marginali* or stereotyp*

AND

Context: infectious disease outbreaks

MeSH term: ‘Disease outbreaks’ or ‘outbreak’

Title/abstract/keyword or .mp.: outbreak or epidemic or pandemic or 'emerging disease' or 'emerging infect*' or 'priority disease*' or 'priority pathogen*' or 'high consequence infectious disease*' or HCID or COVID-19 or Coronavirus or SARS* or 'severe acute respiratory syndrome' or MERS or 'middle east respiratory syndrome' or MERS-CoV or H1N1 or 'swine flu' or H5N1 or ‘pandemic influenza’ or Zika or Ebola or ebolavirus or 'Sudan virus' or 'haemorrhagic fever*' or ‘hemorrhagic fever*' or Marburg or CCHF or Nipah or henipaviral or 'Lassa fever' or Dengue or 'Rift valley fever' or mpox or monkeypox or cholera* or measles or malaria or polio* or plague or 'yersinia pestis’

AND

Measure: scale

Title/abstract/keyword or .mp: scale or survey or questionnaire or tool or cross-sectional or “cross sectional” or cohort or longitudinal or ‘population stud*’ or population-based or prevalence

SOURCES:

Databases searched: MEDLINE, PsycINFO, Global Health, EMBASE, Web of Science, and Cochrane Library

Additional sources: reference lists of relevant systematic reviews and included studies screened

RESTRICTIONS:

No language restrictions

All records available on databases up to date of search (31 January 2023) included

Systematic review search strategy

A.2 Initial stigma typology framework

Initial stigma typology framework

	Prejudice *Endorsement of stereotypes*	**Discrimination** *Differential treatment*
Public stigma	Public prejudice	Public discrimination
Self stigma	Self prejudice	Self discrimination
Structural stigma	Structural prejudice	Structural discrimination
Label avoidance	Anticipated prejudice	Anticipated discrimination

Based on stigma typology developed by Jones and Corrigan[14]

A.3 Assessment of transferability of scales

Stevelink and Van Brakel's Cross-Cultural Equivalence Framework[121] evaluates the transferability of scales across different cultural and contextual settings using the following five domains:

- **Conceptual equivalence:** Achieved when the questionnaire maintains the same relationship to the underlying concept in both contexts, including domains covered and their relative emphasis.
- **Item equivalence:** Present when items estimate the same latent construct and are equally relevant and acceptable in both contexts.
- **Semantic equivalence:** Refers to the transfer of meaning across languages, achieving a similar effect for respondents who speak different languages.
- **Operational equivalence:** The extent to which similar questionnaire formats, instructions, administration modes, and measurement methods can be used.
- **Measurement equivalence:** Whether the psychometric properties of the adapted measure are comparable across contexts.

Each domain was rated as *minimal*, *partial*, or *extensive* based on the evidence reported in included studies.

A scale was considered to demonstrate sufficient cross-cultural equivalence if:

- At least three domains were rated as *extensive*, and
- No domain was rated as *minimal*.

Scales that did not meet this threshold were considered to have *insufficient* evidence of cross-cultural equivalence (Example provided in Table A.2).

Example of application of cross-cultural equivalence framework for cross-national use

Equivalence domain (cross-national use)	**COVID-19-related Stigma Survey**
Conceptual equivalence	Minimal
Item equivalence	Partial
Semantic equivalence	Minimal
Operational equivalence	Partial
Measurement equivalence	Partial
Overall rating	**Insufficient**

Framework based on Stevelink and van Brakel's cross-cultural equivalence domains.[121]
Survey used in India and Bangladesh in this case.[133,136]

As per the COSMIN guideline for systematic reviews of patient-reported outcome measures[105], cross-cultural validity was assessed not only across national or linguistic groups, but also across different outbreaks and respondent groups (e.g. people with and without lived experience of the disease).

A.4 Further details of included studies and respective scales

Further details of included studies and respective scales

Scale[*]	Study 1st author (yr)	Origin of items	Country (language(s))	Study population (n); mode of administration	Relevant methods[†]	Risk of bias rating[§]
COVID-19 stigma scales						
COVID-19-related Stigma Survey	Dar (2020)[133]	Ebola-related Stigma Scale	India (N/S)	Recovered patients (91); self or interviewer (in person)	Scale development	Inadequate
	Kibria (2022)[136]	As above	Bangladesh (Bengali)	Recovered patients (384); interviewer (in person or phone call)	Content validation Internal consistency	Doubtful Doubtful
COVID-19 Stigma Scale	Nair (2022)[135]	HIV stigma scale, HIV stigma framework + news reports	India (Hindi, Tamil, Marathi, Odia, Assamese)	Recovered patients (99); interviewer (phone call)	Scale development Internal consistency Test-retest reliability	Inadequate Doubtful Doubtful
	Adhikari (2022)[137]	As above	India (As above)	Recovered patients (2279); interviewer (phone call)	Scale use only	N/A
Community COVID-19 Stigma Scale	Nair (2022)[135]	HIV stigma scale, HIV stigma framework + news reports	India (Hindi, Tamil, Marathi, Odia, Assamese)	Community members without experience of the illness (61); interviewer (phone call)	Scale development Internal consistency Test-retest reliability	Inadequate Doubtful Adequate
	Adhikari (2022)[137]	As above	India (As above)	Community members without experience of the illness (2279); interviewer (phone call)	Scale use only	N/A
Eight-item Stigma Scale	Mistry (2022)[138]	HIV stigma scale	Bangladesh (Bengali)	All older adult community members (1045); interviewer (phone call)	Content validation Internal consistency	Inadequate Doubtful

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Table A.3 – continued from previous page

Scale*	**Study 1st author (yr)**	**Origin of items**	**Country (language(s))**	**Study population (n); mode of administration**	**Relevant methods†**	**Risk of bias rating§**
Arabic Explanatory Model Interview Catalogue (EMIC)	Al-Zamel (2021)[134]	Developed for leprosy and mental health stigma	Saudi Arabia (Arabic)	Recovered patients (174); interviewer (phone call)	Content validation Structural validation Internal consistency	Doubtful Adequate Adequate
COVID-19 Stigma Instrument-Patients (CSI-P2)	Huang (2021)[139]	HIV stigma scale	China (Chinese)	Recovered patients (151); self (online)	Scale development Structural validation Internal consistency Hypotheses testing	Inadequate Adequate Adequate Very good
The Perceived Courtesy Stigma Sub-scale	Li (2021)[140]	HIV stigma scales + other literature	China (Chinese)	Community members without experience of the illness (2812); self (online)	Scale development Structural validation Internal consistency Test-retest reliability Hypotheses testing	Inadequate Very good Very good Adequate Adequate
The Affiliate Stigma Sub-scale	Li (2021)[140]	HIV stigma scales + other literature	China (Chinese)	Community members without experience of the illness (2812); self (online)	Scale development Structural validation Internal consistency Test-retest reliability Hypotheses testing	Inadequate Very good Very good Adequate Adequate
Modified 12-item HIV stigma scale	Mlouki (2022)[124]	HIV stigma scale + literature review + qualitative interviews	Tunisia (Tunisian Arabic)	Current patients (346); interviewer (phone call)	Scale development Structural validation Internal consistency	Doubtful Very good Very good
Stigma Discrimination Scale (SDS-11)	Haddad (2021a)[123]	HIV stigma scales	Lebanon (English and Arabic)	All community members (405); self (online)	Scale development Structural validation Internal consistency	Inadequate Very good Very good
Self-stigma Scale (SSS-15)	Haddad (2021a)[123]	HIV stigma scale + other literature	Lebanon (English and Arabic)	Recovered patients (49); self (online)	Scale development Structural validation	Inadequate Inadequate
COVID-19 bullying scale	Haddad (2021b)[141]	Bullying scales	Lebanon (Arabic)	All community members (405); self (online)	Scale development Structural validation Internal consistency	Inadequate Very good Very good

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Table A.3 – continued from previous page

Scale*	Study 1st author (yr)	Origin of items	Country (language(s))	Study population (n); mode of administration	Relevant methods†	Risk of bias rating§
COVID-19 Experienced DISCrimination Scale (CEDISC)	Bonetto (2022)[126]	HIV stigma scales	Italy (Italian)	Recovered patients (579); self (online)	Scale development Structural validation Internal consistency Test-retest reliability	Inadequate Very good Very good Adequate
COvid-19 INternalised Stigma Scale (COINS)	Bonetto (2022)[126]	HIV stigma scales	Italy (Italian)	Recovered patients (519); self (online)	Scale development Structural validation Internal consistency Test-retest reliability	Inadequate Very good Very good Adequate
COVID-19 Responsibility Attribution scale	Choi (2022)[142]	Literature review, qualitative interviews, + author experience	South Korea (N/S)	All community members (1000); self (online)	Scale development	Inadequate
COVID-19 Attitudes scale	Choi (2022)[142]	Literature review, qualitative interviews, + author experience	South Korea (N/S)	All community members (1000); self (online)	Scale development	Inadequate
COVID-19-related enacted Stigma Questionnaire	Faghankhani (2022)[131]	HIV + SARS stigma scales, social media analysis + qualitative interviews	Iran (Persian)	Community members without experience of the illness (630); interviewer (phone call)	Scale development Structural validation Internal consistency	Doubtful Adequate Adequate
Discrimination in Medical Settings Scale	Soleimani (2021)[143]	Source not specified	Iran (N/S)	Recovered patients (176); N/S	Scale development Internal consistency	Inadequate Doubtful
30-item Bullying during the COVID-19 Pandemic Questionnaire	Akour (2021)[144]	Literature review + author experience	Jordan (Arabic)	Community members without experience of the illness (397); self (online)	Scale development	Inadequate
Stigmatising Attitudes Scale	Hossain (2021)[145]	Source not specified	Bangladesh (Bengali)	All community members (1056); self (online)	Scale development Internal consistency	Inadequate Doubtful
COVID-19 Stigma Scale (COVID19SS)	Alatrany (2020)[146]	Literature review + author experience	Iraq (Arabic)	All community members (953); self (online)	Scale development Structural validation	Inadequate Inadequate
COVID-19 Perceived Stigma Scale-22 (CPSS-22)	Alchawa (2022)[128]	HIV + cancer stigma scales	Qatar (Arabic and English)	Recovered patients (404); interviewer (phone call)	Scale development Internal consistency	Inadequate Doubtful

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Table A.3 – continued from previous page

Scale*	Study 1st author (yr)	Origin of items	Country (language(s))	Study population (n); mode of administration	Relevant methods†	Risk of bias rating§
Public Attitudes towards Stigma Questionnaire	Almoayad (2020)[127]	Literature review	Saudi Arabia (Arabic)	All community members (847); self (online)	Scale development Internal consistency	Inadequate Inadequate
Perceived Stigmatization of COVID-19 Scale	Babatunde (2021)[132]	HIV stigma scale	Nigeria (N/S)	All community members (333); interviewer (in person)	Scale development Internal consistency	Inadequate Doubtful
Public COVID-19-related Stigma towards Patients with COVID-19 Measure	Jiang (2021)[147]	TB stigma scales	China (Mandarin)	All community members (5039); self (online)	Scale development	Inadequate
Public COVID-19-related Stigma towards Wuhan People Measure	Jiang (2021)[147]	TB stigma scales	China (Mandarin)	All community members (4628); self (online)	Scale development	Inadequate
COVID-19 Public Stigma Scale	Nochaiwong (2021)[57]	Literature review + qualitative interviews	Thailand (Thai)	All community members (4004); self (online)	Scale development Structural validation Internal consistency Hypotheses testing Test-retest reliability	Doubtful Very good Doubtful Very good Adequate
Social stigma and discriminatory attitudes scale	Osei (2022)[129]	HIV stigma literature	Ghana (Local languages)	All community members (3259); interviewer (in person)	Scale development Internal consistency	Inadequate Doubtful
Modified Measure of Disease-Related Stigma (MDRS) scale	Preusting (2021)[148]	Stigma scale used for HIV, cancer, and anorexia nervosa	Netherlands (Dutch)	All adolescents in community (380); self (online)	Scale development Structural validation Internal consistency	Inadequate Very good Very good
The social stigma scale	Wilandika (2022)[149]	Stigma theory	Indonesia (N/S)	Community members without experience of the illness (225); self (online)	Scale development Structural validation Internal consistency	Inadequate Very good Very good
COVID-19 related Social Stigma Scale	El Rakhawy (2021)[150]	Focus groups + literature review	Egypt (Arabic)	All community members (501); self (online)	Scale development Structural validation	Inadequate Inadequate

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Table A.3 – continued from previous page

Scale*	**Study 1st author (yr)**	**Origin of items**	**Country (language(s))**	**Study population (n); mode of administration**	**Relevant methods†**	**Risk of bias rating§**
Long COVID Stigma Scale (LCSS)	Pantelic (2022)[122]	Chronic illness stigma scales + qualitative interviews	United Kingdom (N/S)	Current patients (888); self (online)	Scale development Structural validation Internal consistency Hypotheses testing	Inadequate Very good Very good Adequate
Ebola disease stigma scales						
Ebola-related Stigma Scale	Overholt (2018)[125]	HIV stigma scales	Liberia (Liberian English)	Recovered patients (299); interviewer (in person)	Scale development Internal consistency	Inadequate Doubtful
7-item EVD-related stigma index	Kelly (2019a)[151]	HIV stigma scale	Liberia (Local languages)	Recovered patients (859); interviewer (in person)	Scale development Structural validation Internal consistency	Inadequate Very good Very good
	Kelly (2019b)[60]	As above	DRC (N/S)	Recovered patients and close contacts (207); interviewer (in person)	Internal consistency	Very good
Ebola-related stigma instrument	James (2020)[130]	HIV stigma scale	Sierra Leone (N/S)	Recovered patients (358); self or interviewer (in person)	Scale development	Inadequate
EVD-related stigma scale	Lawry (2022)[61]	Unspecified existing instruments	DRC (Kiswahili and Kinande)	Recovered patients, partners + community members without history of the illness (399); interviewer (in person)	Scale development	Inadequate
Stigma toward EVD Survivors Scale	Antonaccio (2021)[152]	HIV stigma scale	Sierra Leone (Krio)	All community members (1008); interviewer (in person)	Scale development Internal consistency	Inadequate Doubtful
EVD Stigma Index	Davidson (2022)[153]	HIV stigma scale	Sierra Leone (N/S)	Community members without experience of the illness (538); self (in person)	Scale development Internal consistency	Inadequate Inadequate

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Table A.3 – continued from previous page

Scale*	Study 1st author (yr)	Origin of items	Country (language(s))	Study population (n); mode of administration	Relevant methods†	Risk of bias rating§
SARS stigma scales						
SARS Social Life and Services Stigma Self-report Questionnaire	Lee (2005)[52]	Focus groups	Hong Kong (Chinese)	All community members (903); self (posted)	Scale development	Doubtful
SARS Discrimination in the Workplace Self-report Questionnaire	Lee (2005)[52]	Focus groups	Hong Kong (Chinese)	All community members (903); self (posted)	Scale development	Doubtful
Zika Virus Disease stigma scales						
Modified Version of the Knowledge, Attitudes, and Practices Survey Tool on Zika Virus Disease	Gregorio (2019)[154]	WHO survey tool	Philippines (Filipino)	All community-based teachers (609); self (in person)	Scale development Internal consistency	Inadequate Doubtful
Lassa fever stigma scales						
Lassa fever-associated stigmatization scale	Usifoh (2019)[72]	Source not specified	Nigeria (N/S)	All university students and staff in community (600); self (in person)	Scale development	Inadequate
Stigma scales used across multiple diseases						
Stigmatization related to EVD and COVID-19 scale	Cénat (2022a)[55]	WHO reports + Social science and behavioural data compilation	DRC (Lingala)	All community members (1614 then 824); interviewer (in person)	Scale development Internal consistency	Doubtful Doubtful
	Cénat (2021)[56]	WHO studies	DRC, Haiti, Rwanda, Togo (French, Creole, English, Kinyarwanda)	All community members (1267); self (online)	Content validation	Inadequate

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Table A.3 – continued from previous page

Scale*	**Study 1st author (yr)**	**Origin of items**	**Country (language(s))**	**Study population (n); mode of administration**	**Relevant methods†**	**Risk of bias rating§**
	Cénat (2022b)[54]	As above	DRC (Swahili, Lingala, Tshiluba, Kikongo, French, English)	Recovered patients and healthcare workers (563); interviewer (in person)	Content validation	Doubtful

*When no scale name was formally given, the terms used to refer to it in the text were adopted. Each set of items that could be combined to form a composite score was regarded as a scale. Sub-scales not combined into a composite score were regarded as unique scales. †In all cases, scale development includes initial content validation. §Assessed using the COSMIN Risk of bias checklist[106] which uses a modular approach to review study methods. Table updated based on subsequent clarification on risk of bias assessment in updated COSMIN manual.[277] All studies reporting internal consistency without structural validity listed as doubtful for this component.

COVID-19 = Coronavirus disease 2019; EVD = Ebola virus disease; SARS = Severe Acute Respiratory Syndrome; N/S = Not specified; N/A = Not applicable; WHO = World Health Organization; yr = year.

A.5 Ratings of psychometric properties of included scales

Overview of psychometric properties of included scales and certainty of evidence

Scales	Content validity	Structural validity	Internal consistency	Test-retest reliability	Hypotheses testing
COVID-19 stigma scales					
COVID-19-related Stigma Survey[133,136]	indeterminate	not assessed	indeterminate	not assessed	not assessed
COVID-19 Stigma Scale[135,137]	indeterminate	not assessed	indeterminate	insufficient (low certainty)	not assessed
Community COVID-19 Stigma Scale[135,137]	indeterminate	not assessed	indeterminate	insufficient (moderate certainty)	not assessed
Eight-item Stigma Scale[138]	indeterminate	not assessed	indeterminate	not assessed	not assessed
Arabic Explanatory Model Interview Catalogue (EMIC)[134]	indeterminate	sufficient (high certainty)	sufficient (high certainty)	not assessed	not assessed
COVID-19 Stigma Instrument-Patients (CSI-P2)[139]	indeterminate	sufficient (moderate certainty)	sufficient (moderate certainty)	not assessed	sufficient (high certainty)
The Perceived Courtesy Stigma Sub-scale[140]	indeterminate	sufficient (high certainty)	sufficient (high certainty)	sufficient (moderate certainty)	sufficient (moderate certainty)
The Affiliate Stigma Sub-scale[140]	indeterminate	sufficient (high certainty)	sufficient (high certainty)	sufficient (moderate certainty)	sufficient (moderate certainty)
Modified 12-item HIV stigma scale[124]	inconsistent (very low certainty)	sufficient (high certainty)	sufficient (high certainty)	not assessed	not assessed
Stigma Discrimination Scale (SDS-11)[123]	indeterminate	sufficient (high certainty)	sufficient (high certainty)	not assessed	not assessed
Self-stigma Scale (SSS-15)[123]	indeterminate	indeterminate	indeterminate	not assessed	not assessed
COVID-19 bullying scale[141]	indeterminate	sufficient (high certainty)	sufficient (high certainty)	not assessed	not assessed

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Table A.4 – continued from previous page

Scales	Content validity	Structural validity	Internal consistency	Test-retest reliability	Hypotheses testing
COVID-19 Experienced DISCrimination Scale (CEDISC)[126]	indeterminate	sufficient (high certainty)	sufficient (high certainty)	insufficient (moderate certainty)	not assessed
COvid-19 INternalised Stigma Scale (COINS)[126]	indeterminate	sufficient (high certainty)	sufficient (high certainty)	insufficient (moderate certainty)	not assessed
COVID-19 Responsibility Attribution scale[142]	indeterminate	not assessed	not assessed	not assessed	not assessed
COVID-19 Attitudes scale[142]	indeterminate	not assessed	not assessed	not assessed	not assessed
COVID-19-related enacted Stigma Questionnaire[131]	inconsistent (low certainty)	insufficient (moderate certainty)	indeterminate	not assessed	not assessed
Discrimination in Medical Settings Scale[143]	indeterminate	not assessed	indeterminate	not assessed	not assessed
30-item Bullying during the COVID-19 Pandemic Questionnaire[144]	indeterminate	not assessed	not assessed	not assessed	not assessed
Stigmatising Attitudes Scale[145]	indeterminate	not assessed	indeterminate	not assessed	not assessed
COVID-19 Stigma Scale (COVID19SS)[146]	indeterminate	indeterminate	indeterminate	not assessed	not assessed
COVID-19 Perceived Stigma Scale-22 (CPSS-22)[128]	indeterminate	not assessed	indeterminate	not assessed	not assessed
Public Attitudes towards Stigma Questionnaire[127]	indeterminate	not assessed	indeterminate	not assessed	not assessed
Perceived Stigmatization of COVID-19 Scale[132]	indeterminate	not assessed	indeterminate	not assessed	not assessed
Public COVID-19-related Stigma towards Patients with COVID-19 Measure[147]	indeterminate	not assessed	not assessed	not assessed	not assessed
Public COVID-19-related Stigma towards Wuhan People Measure[147]	indeterminate	not assessed	not assessed	not assessed	not assessed
COVID-19 Public Stigma Scale[57]	indeterminate	sufficient (high certainty)	indeterminate	sufficient (moderate certainty)	sufficient (high certainty)
Social stigma and discriminatory attitudes scale[129]	indeterminate	not assessed	indeterminate	not assessed	not assessed

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Table A.4 – continued from previous page

Scales	Content validity	Structural validity	Internal consistency	Test-retest reliability	Hypotheses testing
Modified Measure of Disease-Related Stigma (MDRS) scale[148]	indeterminate	sufficient (high certainty)	insufficient (high certainty)	not assessed	not assessed
The social stigma scale[149]	indeterminate	sufficient (high certainty)	sufficient (high certainty)	not assessed	not assessed
COVID-19 related Social Stigma Scale[150]	indeterminate	indeterminate	indeterminate	not assessed	not assessed
Long COVID Stigma Scale (LCSS)[122]	indeterminate	sufficient (high certainty)	sufficient (high certainty)	not assessed	sufficient (moderate certainty)
Ebola disease stigma scales					
Ebola-related Stigma Scale[125]	indeterminate	not assessed	indeterminate	not assessed	not assessed
7-item EVD-related stigma index[60,151]	indeterminate	indeterminate	indeterminate	not assessed	not assessed
Ebola-related stigma instrument[130]	indeterminate	not assessed	not assessed	not assessed	not assessed
EVD-related stigma scale[61]	indeterminate	not assessed	not assessed	not assessed	not assessed
Stigma toward EVD Survivors Scale[152]	indeterminate	not assessed	indeterminate	not assessed	not assessed
EVD Stigma Index[153]	indeterminate	not assessed	indeterminate	not assessed	not assessed
SARS stigma scales					
SARS Social Life and Services Stigma Self-report Questionnaire[52]	indeterminate	not assessed	not assessed	not assessed	not assessed
SARS Discrimination in the Workplace Self-report Questionnaire[52]	indeterminate	not assessed	not assessed	not assessed	not assessed
Zika Virus Disease stigma scales					
Modified Version of the Knowledge, Attitudes, and Practices Survey Tool on Zika Virus Disease[154]	indeterminate	not assessed	indeterminate	not assessed	not assessed
Lassa fever stigma scales					
Lassa fever-associated stigmatization scale[72]	indeterminate	not assessed	not assessed	not assessed	not assessed

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Table A.4 – continued from previous page

Scales	Content validity	Structural validity	Internal consistency	Test-retest reliability	Hypotheses testing
Stigma scales used across multiple diseases					
Stigmatization related to EVD and COVID-19 scale[54–56]	inconsistent (moderate certainty)	not assessed	indeterminate	not assessed	not assessed

Rating of psychometric properties according to COSMIN criteria for good measurement properties and certainty of evidence based on COSMIN modified GRADE approach.[105,278] Table updated based on subsequent clarification on recommended rating process in updated COSMIN manual.[277] Indeterminate scores no longer given a certainty rating and all internal consistency scores without structural validity listed as indeterminate. Note: No scales assessed responsiveness. Measurement invariance assessed as part of cross-cultural validity. Inconsistent content validity = at least one rating (of comprehensibility, relevance, and comprehensiveness) is + and one is -.[279]

B

Appendices for stakeholder interviews

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B.1 Interview topic guide

Interview topic guide

Focus area	Opening question	Possible probes
Positionality	To start, can you tell me which infectious disease outbreaks you are most familiar with? What was/is your position or role during these outbreaks?	• What outbreak response activities are/were you involved in during the outbreak? • Can you describe the setting in which you carried out these activities? • Were you involved in creating any policies, guidelines, or patient-facing documents during the outbreak? • Were you involved in any research during the outbreak? • Were you involved in coordinating testing and treatment during the outbreak? • Were you involved in any risk communication and community engagement during the outbreak? • Did you personally ever have [disease of concern]? • Did you have contact with people with [disease of concern] during the outbreak? How regular was this contact?
Stigma manifestations	Do you think there is/was stigma associated with this/these outbreak(s)?	If yes: • Can you give some examples of how this stigma was visible in the community? • Do you think there was less or more stigma associated with the disease over time? • What do you think the underlying causes of this stigma were? • Do you think there is still stigma associated with the disease? • Who is affected by this stigma? Is it just patients, or is it broader than that? (Potential prompt: healthcare workers, caregivers, partners?) If no: • What makes you say this? • Were there steps taken to actively prevent stigma from being associated with this outbreak? • We know that stigma is often associated with outbreaks; do you think there are particular features of this outbreak that made it different?

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Table B.1 – continued from previous page

Focus area	**Opening question**	**Possible probes**
Impact of stigma on outbreak control	Do you think the stigma associated with the disease (has) affected control of the outbreak(s)?	• Did stigma impact people getting tested? (If so, how?) • Did stigma impact how well people were treated at health facilities? (If so, how?) • Did stigma impact how well people adhered to treatment? • Did stigma affect the community's trust of healthcare workers or other response workers? • Did people choose to seek testing or treatment outside their own community because of stigma?
Impact of outbreak control on stigma	Do you think any of the outbreak control measures increased stigma? Can you give examples? Do you think any of the outbreak control measures reduced stigma? Can you give examples?	• Potential prompts of possible ways outbreak control pillars contribute to stigma.
Stigma management	Do you have thoughts on how stigma could be better managed or reduced during future outbreaks?	• Do you think education-focused interventions would be beneficial? How do you envisage this being implemented? • Do you think having more patient advocacy from people who have had the disease would be helpful?
Stigma assessment	Are you aware of any measures such as surveys or scales that were used to assess stigma in the outbreak(s)? If yes: Can you describe what you can remember about these measures?	• How long after the start of the outbreak was the measure used? • Was it used more than once? • Do you know what the measure was used for? • Was there anything you thought was good about the measure? • Was there anything that could be improved about the measure used?
Uses of a stigma scale	Our team are in the early stages of developing an outbreak stigma scale that consists of standardised questions that can be used across different settings and outbreaks to assess stigma, with some additional context-specific questions. Do you think this would be useful in your setting/the setting(s) we've discussed?	• If yes, what do you think it could be used for? • If no, why not?

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Table B.1 – continued from previous page

Focus area	Opening question	Possible probes
Optimal design of stigma scale	For the setting(s) we've discussed, what kind of questions do you think it would be important to ask in a stigma scale?	• Potential prompt with examples of questions. • Do you think the scale should be designed for patients only or for anyone in the community (why)? • What is the maximum amount of time you think it should take to complete the questions?
Operationalisin the scale	If your organisation/group were interested in using a measure like this, what processes would it need to go through before it is used?	• Do you think using a stigma scale as we've discussed would be feasible for your organisation/group to use? What would the major barriers to its use be? • Do you think a stigma scale would be acceptable to the communities you've worked with? Reasons for answer. • Who would be best positioned to administer the scale in the setting? (e.g. self-administer or interviewer)
Other	Do you have any final thoughts on measuring stigma in the outbreak you described?	• Do you want to add to anything we've discussed in this session?

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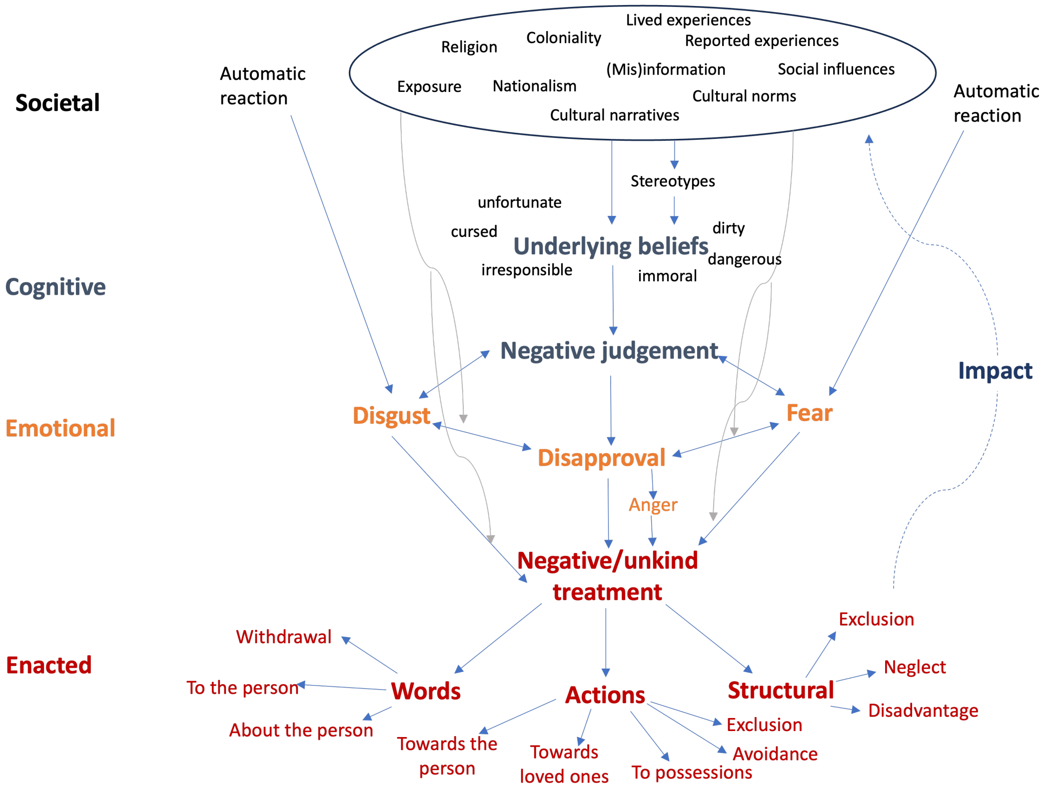
B.2 Early iteration of stigma model



Early iteration of stigma model

B.3 Illustrative quotes for pre-existing contextual factors

Illustrative quotes for pre-existing contextual factors

Contextual factors	**Illustrative quotes**
Societal	
Evolutionary processes	*"I think one of the salient features of human and social responses to infectious diseases going back for thousands of years, is that it was often the case that it was obvious for one reason or another who was infected with certain pathogens, or at least who had a certain type of disease syndrome."* – Interview 5, Multi-outbreak health ethicist and policy advisor
Coloniality	*"I believe that there's a historical memory around the colonial medical practices, let's say, or vaccination practices or massive treatment campaigns that is still there."* – Interview 23, International response coordinator
Politics	*"This message was echoed by some of the opinion leaders, like members of parliament who are saying, no, this is a hoax, this is a hoax for the government to get money from donors."* – Interview 14, COVID-19 and Ebola disease response trainer and psychosocial lead *"Whether these things are going to be labelled and perceived as a pandemic are also very politically and socially constructed."* – Interview 32, Multi-outbreak public health practitioner and community advocate
Perceived cultural hierarchy	*"There was also the "we can't use masks" at the beginning of the pandemic because "culturally we're different". It was kind of this cultural superiority, this idea that people were somehow different, even though I think Covid, as it swept across the world, demonstrated that we're not very different at all."* – Interview 10, Multi-outbreak clinician-researcher
Religion and belief systems	*"For instance, where there were clusters of infections... there was an allegation that the Muslim community exhumed a body that had been buried by a burial team to perform the religious rituals of burial. So that was the point at which we brought in the religious leaders to fully understand the risk of not following the due process. I think this is important: had the Muslim leaders been adequately informed and prepared and convinced that actually the right religious burial rites had been followed... we probably would not have seen those clusters of infection where we've had as many as 20 new cases in one day. So I don't think we adequately engaged them."* – Interview 14, COVID-19 and Ebola disease response trainer and psychosocial lead

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Contextual factors	**Illustrative quotes**
Historical associations	*"So I think blood does have a broader meaning than just as a bodily fluid. It holds all sorts of ritualistic and cultural ideas about cleanliness and lineage. And, you know, it's a very, very complex substance and contamination by blood and we think about that everywhere in the West, you know, it has been historically stigmatised."* – Interview 2, Multi-outbreak anthropologist
Community	
Social unity or divides	*"I think in the South African context, it's always complex. But there was a very strong sense of, 'poor people live in crowded communities, poor people have a particular demographic in our country, and they were the ones that were driving the pandemic' from people who were able to protect themselves behind high walls and in smart houses, even though they were also getting sick."* – Interview 1, COVID-19 testing centre coordinator *"So in Congo, in the west, you have basically two primary communities. You have the Indigenous community and the non-Indigenous community, and survival rates were much lower for the Indigenous community because they're slower to seek care and that is a result of stigma, but not stigma about Ebola, about being a person who experiences stigma within that community and discrimination. So yeah, it blurs into the social determinants of health at some point."* – Interview 16, International outbreak response coordinator
Intersecting identities	*"There was definitely an obesity-related stigma I think, that you know people have done it to themselves and made themselves sick and put other people at risk because they hadn't been able to control their weight."* – Interview 1, COVID-19 testing centre coordinator *"This virus will show up all the weaknesses in your systems. Every system, every weakness. At some point it's about to stare you in the face because that's what outbreaks do. And that's exactly what SARS-CoV-2 did. Of course it did. And part of that was the vulnerable populations."* – Interview 11, Multi-outbreak response coordinator
Cultural practices	*"This I believe, also: that the western gaze onto the people who are affected by these diseases is limited. We do not realise what the real reason for stigma is… because I don't think that people feel fear or stigmatised because of the disease in itself, always. I'm not denying that is there, but in fact, sometimes what they fear most is stigma by their own community because they do not play the role for which they are meant to under their social codes, which is to take care of your sick relatives until death, you know, and even beyond that… You know, so for them, they are embarrassed, not because they are Ebola infected, but because in front of their community, because they couldn't take care of their people."* – Interview 23, International response coordinator

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Table B.2 – continued from previous page

Contextual factors	Illustrative quotes
Competing concerns	*"In Sierra Leone, you have one of the highest maternal mortality and infant mortality rates in the world outside of Ebola. A mother has five, six kids. They live upcountry. They do not have access to healthcare on a simple basis. They have to survive the way they can through caring for their relatives within a small community, and all of a sudden they are told that you may not care for your relatives because you're going to become infected... So it's like, look, I'm going to die one way or another and in this country, in this life, me and my people are at very high risk of dying from any other disease, because there's no prevention, there's no access to health care. So why should I get that excited, you know?"* – Interview 23, International response coordinator
Collective memory	*"In Southeast Asia, where these events have happened in the past, people are usually more prepared in a way or sometimes more cautious. And in the airports, for example, it's almost customary to wear a mask. So in the beginning, people that were early adopters in a way, and wearing masks, they were also being looked at in a way that was not as much... public stigma."* – Interview 17, COVID-19 psychosocial responder and stigma researcher
Institutional	
Laws and policies	*"The border closures to Africa in response to Omicron were, I think, an example of where prejudicial views about African populations and views about Covid coincided."* – Interview 5, Multi-outbreak health ethicist and policy advisor *"So in the UK when we are talking about when Section 28 happened, when you weren't allowed to talk about your gender and sexual orientation in schools. So that automatically created this value of, you know, oh, being gay, being LGBTQ+ is a bad thing. So when a condition impacts those communities, automatically people think that, oh, of course, gay communities. So this is very much related."* – Interview 7, Community advocate with lived experience of mpox
Existing (mis)trust	*"I think there's something about trust in science and whether people have a background where they feel that they've been treated fairly."* – Interview 18, COVID-19 and TB stigma researcher and policy advisor
Relational	
Shared stories	*"Sometimes we will get situations where someone adversely reacts to a vaccine and that happens like 1 in 1,000,000, you know. But then that will become their point of attachment."* – Interview 13, Medical doctor and Ebola survivor

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Table B.2 – continued from previous page

Contextual factors	**Illustrative quotes**
Social norms	*“The reliance on social groups or the social coherence and is it a rather individualistic culture or not? Things like that play a role in how you conceptualise the idea of stigma or the expectations of your social surroundings. And this might also be taken into account when thinking about stigma for infectious diseases from a global perspective.”* – Interview 17, COVID-19 psychosocial responder and stigma researcher *“You behave in a way because you think your community behave in that way.”* – Interview 2, Multi-outbreak anthropologist
Family dynamics	*“Initially the African way of doing things is if you lose your parents then somebody like an uncle actually takes you in to live as his child. And that’s what was happening in West Africa. People were dying and then the children were moving to other families and from there they would start infections and so on and so forth. So what developed out of that now, nobody wanted to look after anybody’s child even if they were discharged from the [Ebola Treatment Unit]. Nobody wanted to take care of them.”* – Interview 15, Viral haemorrhagic fever clinical trainer and responder
Individual	
Lived experiences	*“You know, two people can be affected by the same pathogen, but their lived experience is different. And therefore, when we’re reading our health statistics, you know, we have decided to classify diseases using pathogens but that in itself is already an impoverishment of data because the lived experiences can be quite radically different. And these are things that often get missing in the so-called evidence-based policy making. Because the evidence you’re using is already selected and filtered.”* – Interview 21, Multi-outbreak health ethicist
Resilience	*“For me as a person, from my point of view, I thought it was just a knowledge gap on their side that they would stigmatise us. Me, I didn’t take it seriously in my mind. I work in the [Ebola Treatment Unit] and here I am a survivor.”* – Interview 27, COVID-19 clinical responder and Ebola survivor programme lead
Agency	*“All the models with fear appeals and the general finding across different areas is that fear appeals themselves are not as effective as they could be if they are not accompanied by aspects strengthening the coping responses at the same time to really provide appropriate and easily actionable steps that can be taken that are easy to do.”* – Interview 17, COVID-19 psychosocial responder and stigma researcher

B.4 Illustrative examples of stakeholder suggestions for stigma assessment tools

Illustrative examples of stakeholder suggestions to enhance the usability and utility of stigma assessment tools for outbreak settings

Examples of suggestions to optimise tool usability	**Examples of suggestions to optimise tool utility**
Content	
• Favour items that are likely to still be relevant in future outbreaks to facilitate preparedness: *“The best thing to do within [my response organisation] is to say, ‘Okay, when we have an outbreak, this is what we plan to do’. And you write up a protocol and you run it past the [ethics review board] ahead of time, is what they would like you to do. And then the [review board] will always say, ‘But you haven’t filled in the specifics: Which population are we talking about, when and who?’ And so then you fill in all the blanks come the epidemic and they can see that they’ve reviewed everything except the blanks and they should be able to give an expedited review.”* – Interview 19, Viral haemorrhagic fever response coordinator	• Include questions about employment: *“I’m saying the workforce and not necessarily healthcare workers, but people who are like previously employed and then they’re getting back into the employment. And we want to know to what extent that has affected their ability to work or their functionality at their places of work.”* – Interview 22, Ministry of Health official
Item phrasing	
• Consider the sensitivity of questions for respondents who have experienced stigma: *“And I think that’s also very difficult to developing a stigma scale is the sensitivity of the issues that you’re dealing with.”*– Interview 20, International governance and policy advisor	• Account for challenges with getting honest responses/consider social desirability bias: *“We find that [social desirability] is an elephant in the room, and that was really difficult… That’s a limitation of the work.”* – Interview 33, Health stigma researcher

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Table B.3 – continued from previous page

Examples of suggestions to optimise tool usability	Examples of suggestions to optimise tool utility
Tool length	
• Ensure short enough to be combined with other tools: *“What I would be doing realistically is bundling this with other assessments… So I would want to see, okay, can I bundle this in with community perception surveys? Can I bundle this in with like a mental health or psychosocial support approach? Can I bundle it in with reentry?”* – Interview 16, International outbreak response coordinator	• Ensure the results provide enough detail to meaningfully inform development of interventions: *“I just wonder, are there ways to use this scale and guide people towards actually identifying action points and intervention points and to sort of say to them, look, this might feel really big. But because it’s such a big problem, we need to look at different points.”* – Interview 18, COVID-19 and TB stigma researcher and policy advisor
Further development considerations	
• Consider combining with qualitative interviews (although highlighted by others that conducting qualitative interviews requires substantially more training): *“The kind of training that you need to do to, you know, get responses for a few questions that have been predetermined versus the kind of training that you need to give to someone to conduct a good qualitative interview are two very different tasks.”* – Interview 18, COVID-19 and TB stigma researcher and policy advisor	• Explore having additional disease or context specific questions or modules: *“So I could imagine that if somebody was looking for a tool to use in [sexually transmitted infections], for example, that they might want to have it slightly more specific and take that context into account as well. And so in that case, so adding in, I don’t know, another five questions or so that were more specific I think is a better solution than to say, okay, now we need a whole separate specific tool because by and large those tend to be an 80% generic and then another 20% may be specific and that that is often true for other instruments as well.”* – Interview 6, Infectious disease stigma researcher
Validation sampling frame	
• Consider non-response bias: *“Some of the people answering the questions may not want to… It may be very hard for them to answer questions about themselves and their activity.”* – Interview 20, International governance and policy advisor	• Position at the community level (while still including self stigma questions): *“There are currently no methods of assessing the effectiveness of [Ebola disease reintegration programmes]… only anecdotes from the community of stigma reducing, but hopefully that will be in place in time for the next outbreak.”* – Interview 14, COVID-19 and Ebola disease response trainer and psychosocial lead

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Examples of suggestions to optimise tool usability	**Examples of suggestions to optimise tool utility**
Administration	
• Avoid paper or tablet self-administered surveys in settings where there is concern about disease transmission through indirect contact: *"So in data collection methods you have to be mindful of using tablets or mobile phones where there's limited, maybe interface with the community that is potentially having an infectious disease."* – Interview 14, COVID-19 and Ebola disease response trainer and psychosocial lead	• Consider emotional toll on interviewers: *"We had to go and get extra counselling for the people doing the interviews with people who are affected by TB because the stories that they were hearing were so traumatising."* – Interview 18, COVID-19 and TB stigma researcher and policy advisor
Methods	
• Allow for iterative refinement and changes to tool throughout testing: *"There's a challenge between having a standard scale and also having sort of an iterative tool where you might have a standard scale, but you might adapt it based on initial feedback. You might do initial sort of 50 people and see what they said and then reiterate it and do some more some more in-depth analysis."* – Interview 9, Multi-outbreak clinical research lead	• Ensure robust psychometric validation with directly affected community members: *"A lot of these things, which is understandable, have been developed quite quickly to get an idea of stigma with an ongoing situation and then adapting existing scales to the Covid-19 situation or changing them throughout the pandemic or developing some new scales... So a lot of these things were kind of developed on the fly or adapted from example, from mental health stigma scales... and so what they are lacking is a proper psychometric validation in many cases."* – Interview 17, COVID-19 psychosocial responder and stigma researcher

B.5 Illustrative examples of stakeholder suggestions for stigma reduction

Stakeholder suggestions for reducing outbreak-related stigma across preparedness, response, and recovery phases

Preparedness	**Response**	**Recovery**
Knowledge exchange		
• Avoid disease names linked to places or animals: *"The viral memes that go around of pictures of monkeys and this idea of people having sex with them… you know, it's not funny to the people who are on the receiving end."* – Interview 8, mpox non-governmental response coordinator and community advocate	• Avoid fear-based messages: *"Stop using fear appeals as a communication technique during outbreaks. Don't do that. It perpetuates stigma. It is really harmful."* – Interview 4, Multi-outbreak behavioural scientist	• Provide recovery information for employers/educators: *"Many times people are just out of their jobs. They're not allowed to be given their jobs again, those that have been working… we can talk with them, with the employers and ask them to be accepted back."* – Interview 22, Ministry of Health official
Policy & service design		
• Design facilities to optimise safe contact with loved ones and healthcare workers: *"Facilities should be designed such that they ease the access of health workers without them having donned protective clothing. And the same for the relatives."* – Interview 34, Health facility manager	• Treat personal items respectfully and allow for retention when possible: *"So they would throw away everything that belonged to you then. Only this very last outbreak, I saw that when you were discharged, they were thinking about returning gadgets, like phones."* – Interview 15, Viral haemorrhagic fever clinical trainer and responder	• Reduce visibility of follow-up services: *"Usually in Ebola, the organisations bring very good new cars, Land Cruisers. And so, when Land Cruisers go to visit a particular person in the community, it arouses a lot of concern, and we should minimise it... If we have to go there, go there as nobody. I think it is important to decrease stigma that we should make our workers as normal as possible."* – Interview 35, Multi-outbreak clinical lead

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Table B.4 – continued from previous page

Preparedness	**Response**	**Recovery**
Psychosocial support		
• Pre-plan psychosocial support programmes: *"I think that the whole question of human behaviour is just so fundamentally missed in a lot of outbreak responses, like we just start chasing pathogens rather than helping humans."* – Interview 16, International outbreak response coordinator	• Involve support teams early: *"Psychosocial counselling has to be thought of immediately."* – Interview 27, COVID-19 clinical responder and Ebola survivor programme lead	• Check psychosocial wellbeing at follow-up: *"These people suffered quite a lot… So I think [what is needed is] to follow up these people in regards to the psychosocial."* – Interview 27, Ebola disease and COVID-19 clinical responder and Ebola survivor programme lead
Community involvement and advocacy		
• Involve local responders in planning and response to ensure sensitivity to community concerns: *"The trial recruited mainly local people for the social science team and the community engagement team... many of them had already worked on the Ebola response, so they were very, very knowledgeable about stigma and the issues that people suffered."* – Interview 2, Multi-outbreak anthropologist	• Involve survivors/recovered individuals in community outreach roles *"I don't think those who came later, like after me, experienced it like I did because by the time they came, I think the psychosocial team had used me, like taking me to the community. They showed people that I'm free. I shared my experience."* – Interview 30, Ebola survivor and peer support lead	• Support peer-led recovery/survivor groups: *"I created an association of survivors… It is still moving and is still on ground fighting discrimination and stigma. We visit each other with these families that lost their relatives in the outbreak. We take care of the kids or orphans of the deceased as an association."* – Interview 30, Ebola survivor and peer support lead

C

Appendices for assessment tool development

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C.1 Stigma variants considered in tool development

Stigma variants considered in tool development

Stigma variant	**Explanation**
Potential actors	
Social	Stigmatisation by family, friends, and other members of the public. Manifestations noted to differ during illness and after recovery.
Provider/authority-related	Stigmatisation by occupational groups designated to provide a service to one's community.
Structural	Both intentional and unintentional private and public institutional rules and regulations that discriminate against individuals with stigmatised conditions.
Self	The result of an individual's internalisation of negative stereotypes, prejudice, or discrimination towards them. This includes shame and diminished self-worth.
Manifestations	
Attitudes & judgement	Biased perceptions, assumptions, or moral evaluations.
Language & communication	Use of words, tone, or messaging (intentional or not) that reinforces stereotypes and marginalisation.
Behaviours & harm	Observable actions that cause physical or social harm, including aggression and mistreatment.
Disadvantage & exclusion	Denial of equal access to resources, opportunities, or participation in social, economic, or institutional settings.
Unwarranted avoidance	Withdrawal or distancing from individuals or groups not grounded in actual risk.
Time point	
Initial	Stigma during illness or outbreak.
Enduring	Ongoing stigma following recovery or end of outbreak.
Potential targets	
Person(s) with illness	Initial stigmatisation of person diagnosed with the illness of concern at the time of illness.
Recovered person(s)	Enduring stigmatisation of person previously diagnosed with the illness of concern after recovery.
Associated person(s)	Stigmatisation of people associated with illness or those diagnosed with the illness even if they may not have the illness themselves (e.g. family members, healthcare workers, demographic/geographic association).

C.2 Use of distancing techniques in item generation

Distancing techniques (sometimes called third-person or indirect techniques) are used to depersonalise potentially sensitive issues in interviews and surveys.[220,280] Participants will not be asked about their personal experiences of being stigmatised or stigmatising others (although they may draw on these to answer) but instead will be asked about their perceptions of stigma within the community. An example is provided below.

Example of rephrasing of stigma scale items using distancing technique

Direct questions	Question adapted using distancing technique
Direct item about being stigmatised: I am looked down on because of [X disease] **Direct item about stigmatising behaviours:** I look down on people with [X disease]	**Item applicable to those being stigmatised and those condoning stigma:** People who have [X disease] are looked down on 3 = Yes 2 = Probably 1 = Unlikely 0 = No

Advantages of using a distancing technique

- Reduces the risk of the survey being distressing for participants who have experienced stigmatisation.
- Avoids questions being perceived as accusatory by those who may condone prejudice and discriminatory behaviour, minimising social desirability bias.[2]
- Recognises that individuals may both experience and perpetuate stigma in different interactions, rather than forcing a false dichotomy of ‘stigmatised vs.

stigmatiser'.[25]

- Allows for easy triangulation of findings from different perspectives (e.g. recovered individuals and indirectly affected community members).
- Increases the sampling frame and provides flexibility in emerging outbreaks where sample sizes of recovered individuals may be small and research fatigue a concern, while still allowing inclusion of lived experience perspectives when available.
- Decreases the impact of non-response bias, as participants' reports about community attitudes can reflect the experiences of groups not directly represented in the sample.
- Focuses on perceived and anticipated stigma, which have important implications for public health, particularly due to their impact on healthcare-seeking behaviour.
- Decreases the risk of stigma surveys inadvertently worsening stigma.

Limitations of distancing techniques

- Does not allow direct measurement of how many individuals have personally felt stigmatised or would personally stigmatise others.
- Prevents direct before-and-after stigma assessment at an individual level.
- Items and findings may be more abstract and difficult to conceptualise.

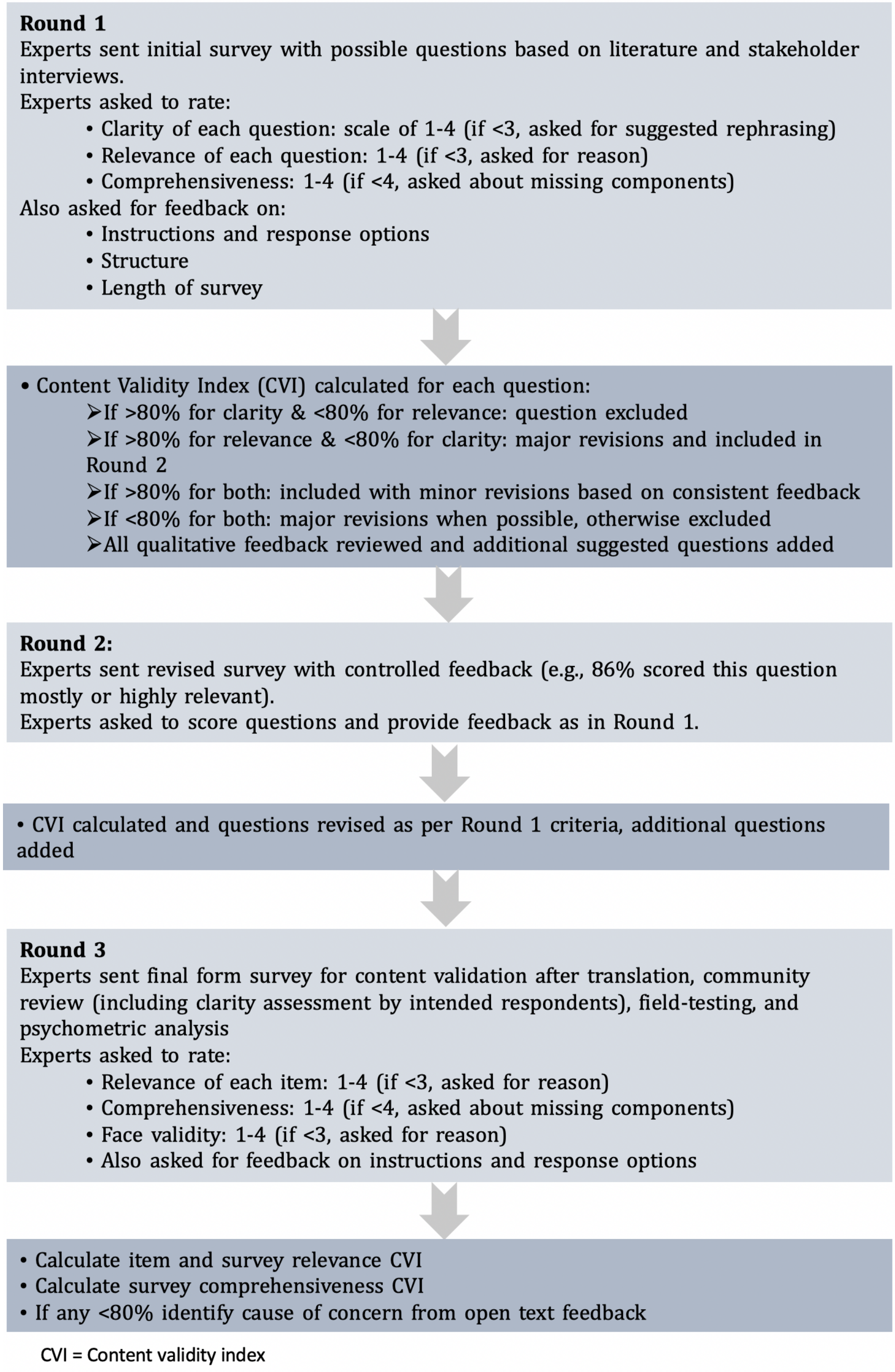
C.3 Characteristics of expert Delphi panellists

Characteristics of expert Delphi panellists

Expert characteristics	**Round 1 (N = 41)**	**Round 2 (N = 39)**	**Round 3 (N = 35)**
WHO region*			
African Region	9	9	8
Region of the Americas	6	5	5
Eastern Mediterranean Region	2	2	2
European Region	10	9	6
South-East Asia Region	8	8	7
Western Pacific Region	6	6	6
Outbreak response experience (disease$^{\$}$)			
Ebola disease and other filoviruses	12	11	11
Mpox and other orthopoxviruses	12	10	8
COVID-19	40	38	33
Other novel coronaviruses (SARS, MERS)	5	5	5
Nipah virus and other henipaviruses	4	4	4
Zika virus	5	5	5
Influenzae (all strains)	6	6	6
Cholera	5	5	5
Dengue	7	7	7
Plague	1	1	1
Hepatitis (A or E)	2	2	2
Chikungunya	1	1	0
Outbreak response experience (location)			
Local (in-country)	35	34	30
Regional/Global	10	9	6
Role in outbreak			
Psychosocial response team	11	11	10
Clinical response team	12	11	10
Social science research	25	25	21
Clinical research	11	10	8
Risk communication and community engagement	20	18	16
Patient advocacy	6	5	4
National policy and coordination (e.g. Ministry of health)	9	9	8
International policy and coordination (e.g. WHO)	8	8	6

*Coded by nationality, 10 experts from each region invited to provide feedback. $^{\$}$Original list based on WHO R&D blueprint[83] with option to specify ‘other’. Experts could select more than one option for all categories.

C.4 Details of Delphi process



Round 1
Experts sent initial survey with possible questions based on literature and stakeholder interviews.
Experts asked to rate:

- Clarity of each question: scale of 1-4 (if <3, asked for suggested rephrasing)
- Relevance of each question: 1-4 (if <3, asked for reason)
- Comprehensiveness: 1-4 (if <4, asked about missing components)

Also asked for feedback on:

- Instructions and response options
- Structure
- Length of survey

- Content Validity Index (CVI) calculated for each question:
  - ➢If >80% for clarity & <80% for relevance: question excluded
  - ➢If >80% for relevance & <80% for clarity: major revisions and included in Round 2
  - ➢If >80% for both: included with minor revisions based on consistent feedback
  - ➢If <80% for both: major revisions when possible, otherwise excluded
  - ➢All qualitative feedback reviewed and additional suggested questions added

Round 2:
Experts sent revised survey with controlled feedback (e.g., 86% scored this question mostly or highly relevant).
Experts asked to score questions and provide feedback as in Round 1.

- CVI calculated and questions revised as per Round 1 criteria, additional questions added

Round 3
Experts sent final form survey for content validation after translation, community review (including clarity assessment by intended respondents), field-testing, and psychometric analysis
Experts asked to rate:

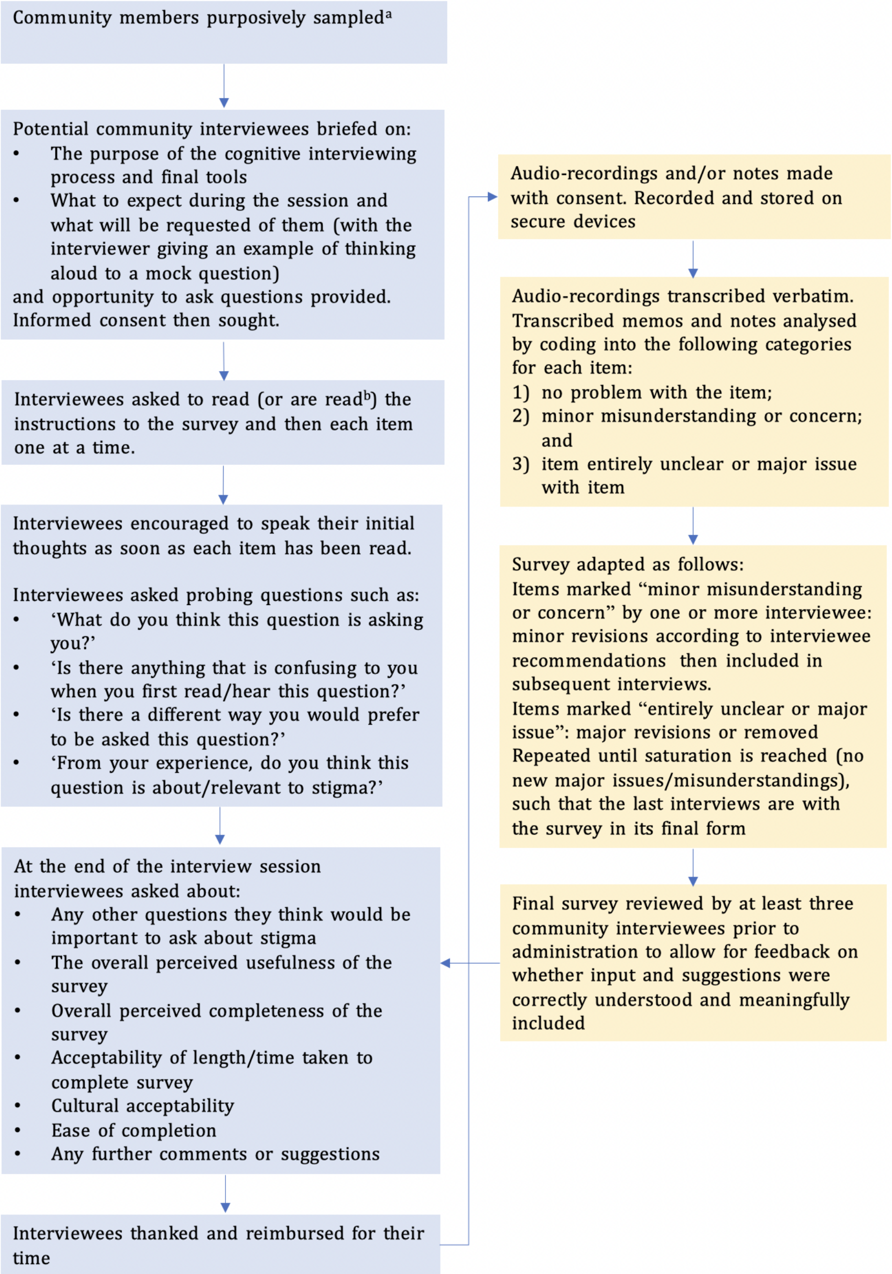
- Relevance of each item: 1-4 (if <3, asked for reason)
- Comprehensiveness: 1-4 (if <4, asked about missing components)
- Face validity: 1-4 (if <3, asked for reason)
- Also asked for feedback on instructions and response options

- Calculate item and survey relevance CVI
- Calculate survey comprehensiveness CVI
- If any <80% identify cause of concern from open text feedback

CVI = Content validity index

Flowchart of Delphi process

C.5 Details of cognitive interview methods



Community members purposively sampled[a]

Potential community interviewees briefed on:
- The purpose of the cognitive interviewing process and final tools
- What to expect during the session and what will be requested of them (with the interviewer giving an example of thinking aloud to a mock question)

and opportunity to ask questions provided. Informed consent then sought.

Interviewees asked to read (or are read[b]) the instructions to the survey and then each item one at a time.

Interviewees encouraged to speak their initial thoughts as soon as each item has been read.

Interviewees asked probing questions such as:
- ‘What do you think this question is asking you?’
- ‘Is there anything that is confusing to you when you first read/hear this question?’
- ‘Is there a different way you would prefer to be asked this question?’
- ‘From your experience, do you think this question is about/relevant to stigma?’

At the end of the interview session interviewees asked about:
- Any other questions they think would be important to ask about stigma
- The overall perceived usefulness of the survey
- Overall perceived completeness of the survey
- Acceptability of length/time taken to complete survey
- Cultural acceptability
- Ease of completion
- Any further comments or suggestions

Interviewees thanked and reimbursed for their time

Audio-recordings and/or notes made with consent. Recorded and stored on secure devices

Audio-recordings transcribed verbatim. Transcribed memos and notes analysed by coding into the following categories for each item:
1) no problem with the item;
2) minor misunderstanding or concern; and
3) item entirely unclear or major issue with item

Survey adapted as follows:
Items marked “minor misunderstanding or concern” by one or more interviewee: minor revisions according to interviewee recommendations then included in subsequent interviews.
Items marked “entirely unclear or major issue”: major revisions or removed
Repeated until saturation is reached (no new major issues/misunderstandings), such that the last interviews are with the survey in its final form

Final survey reviewed by at least three community interviewees prior to administration to allow for feedback on whether input and suggestions were correctly understood and meaningfully included

a = to include recovered persons, household members/close contacts, response workers, and other community members. b = depending on literacy and personal preference

Flowchart of cognitive interviews

C.6 Sampling, administration, and data management at each study site

Uganda

In Uganda, initial cognitive interviews took place in the city of Entebbe. This location was selected as it was affected by the 2022 Ebola disease outbreak, but on a smaller scale than the final survey administration sites of Mubende and Kassanda. This reduced the risk of resampling during survey administration. It was also selected because Luganda and English are the most commonly spoken languages.

Prior to administration of the final survey, seven data collectors attended a full-day study specific training workshop before recruitment. Training was co-led by an investigator with personal experience of Ebola disease. Following training, data collectors administered the surveys in the relevant communities, using a side-by-side interviewing approach when appropriate. A counsellor with training and experience in providing psychosocial support to Ebola survivors travelled with the team during data collection to mitigate any distress and offer psychosocial support referrals if needed. Survey respondents were recruited from the most affected areas in the 2022 Ebola disease outbreak, namely Mubende and Kassanda districts, and the Mubende-border of the Kyegegwa district (Table C.4). Sampling included all eligible Ebola survivors in the area who were in contact with local support networks (51 out of 87 total adult survivors),[281] up to two household members per affected household, 110 available clinical care providers and outbreak response support staff still residing in the area, and other community members who were in the affected districts during the outbreak to make up the minimum sample size of 300, after accounting for overlap in categories.

Central Uganda respondents by district

District	No. respondents n (%)
Kassanda	145 (48)
Mubende	145 (48)
Kyegegwa	12 (4)

Data were collected and stored directly on REDCap when possible, and via paper forms when there was no internet connectivity. Paper forms were transferred onto the REDCap platform at the end of each day by the research team, with manually entered data checked against the original forms by the project leads. Open-text responses were written or typed by data collectors and professionally translated.

UK

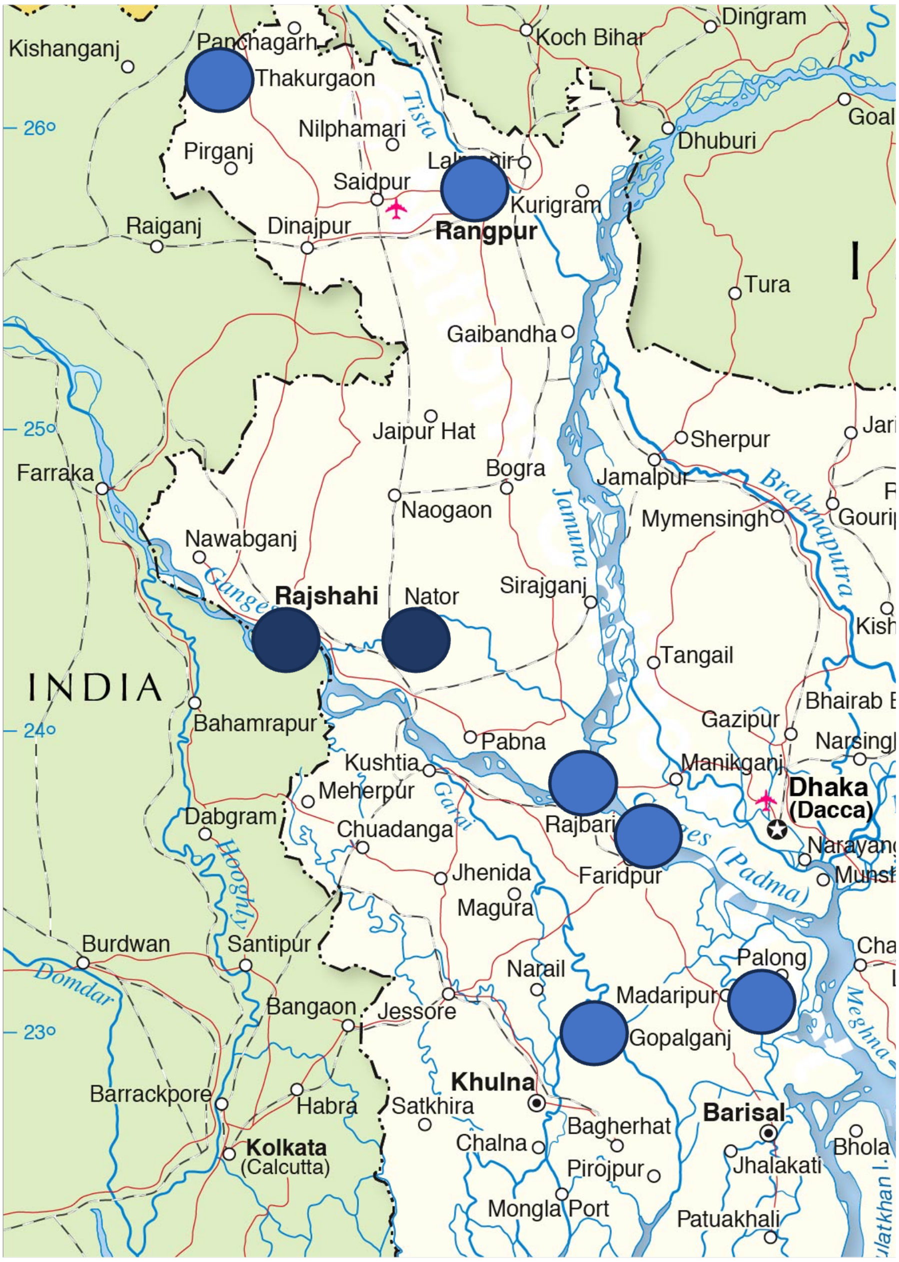
In the UK, initial cognitive interviewing was conducted via Microsoft Teams. However, for the final survey administration online data collection was considered more appropriate based on discussion with community collaborators. This limited how precise the sampling of different respondent categories could be. Approximate quotas were established for (a) community members considered at higher risk (predominantly GBMSM) (78% of sample) and (b) healthcare workers (including those who also identify as GBMSM) (22% of sample), as key groups eligible for the national mpox vaccination programme at the time.[206] Quotas were based on estimated population sizes for these population groups in the UK.[282–285] Since sampling was non-probabilistic, it served as a guide for recruitment logistics rather than an enforced measure for ensuring generalisability. On the online survey platform Prolific, filters were used for UK residents who identify as LGBTQ+ men or as healthcare workers, applying the above quota proportions.

Respondents were also recruited through social media (with individual HIV and LGBTQ+ advocates sharing the survey details) and institutional mailing lists of local HIV and LGBTQ+ organisations and sexual health and outbreak response professional networks. Following consultation with community contributors and field experts, we did not exclude individuals who engaged with these recruitment channels and were aware of mpox, but who did not identify as LGBTQ+ men or healthcare workers in the survey. This decision aimed to maximise inclusivity, in recognition that the outbreak was not confined to these groups. Details of local support organisations and helplines were provided at the start and end of the survey. All data were collected and stored directly on REDCap. Open-text responses were typed by respondents.

Bangladesh

In Bangladesh, cognitive interviewing and survey administration was incorporated into the icddr,b's existing Nipah survivor follow-up programme. Five data collectors attended two half-day training sessions that were facilitated by myself and the local lead (Tonmoy Sarkar). Thirty survivors who met the eligibility criteria were identified across eight districts. The data collection team also interviewed two household members of each survivor and four community members from the same village or town. Three medical facilities which have treated people with Nipah were identified across these districts. At each facility the data collection team interviewed 10 doctors, 10 nurses, and 10 community health workers or support staff. Psychosocial support was available to respondents with referral if necessary.

Data were collected and stored directly on REDCap when possible, but paper forms were often required due to no internet connectivity. Scans of paper forms were uploaded to OneDrive and captured on REDCap by myself and a research assistant (Ann Hui Ching) and then checked for accuracy against the original form. Open-text responses were audio-recorded and then transcribed and translated by the icddr,b research team. For Nipah survivors, this was combined with an additional qualitative component developed by the local research team.



Map of data collection sites in Bangladesh. Darker dots indicate sites where data collection was delayed (collected in September rather than July) due to political unrest. Map sourced from Nations Online Project,[286] with reuse permitted for educational purposes; dots indicating data collection sites added by the author.

C.7 Details of attention checks

Two attention checks were integrated into the online surveys. In keeping with recommendations for attention checks, this included one short Instructed Manipulation Check (IMC), and one instructed response item (IRI).[287]

The IMC is typically a standalone question and in this case was phrased as: “To show you are paying attention, please select ‘All’ as your response to this item”, with a single choice option of ‘None’, ‘A few’, ‘About half’, ‘Most’, and ‘All’.

The IRI is typically embedded into a list of other items of the same format. In this case, it was included as a last item in the draft RAPID scale items and was phrased as “Please choose ‘Yes’ for this item to show you are paying attention”, with the options of ‘Yes’, ‘Probably’, ‘Unlikely’, and ‘No’.

Respondents who failed either of the attention checks were excluded from analyses.

C.8 Weighted CFA sensitivity analyses

Population estimates used for survey weightings were based on publicly available sources where possible[282,283,285,288–298] and local stakeholder estimates when not available.

Comparison of unweighted and weighted model standardised factor loadings

Factor	Item/Fact	Unweighted model est.std (95% CI)	Weighted model est.std (95% CI)	Difference
F1	C1	0.76 (0.70–0.82)	0.73 (0.60–0.85)	-0.03
F1	C2	0.64 (0.58–0.71)	0.64 (0.49–0.78)	0.00
F1	C3	0.82 (0.77–0.88)	0.98 (0.83–1.12)	0.16
F2	C4	0.72 (0.65–0.79)	0.64 (0.54–0.74)	-0.08
F2	C5	0.87 (0.82–0.92)	0.95 (0.89–1.01)	0.08
F2	C6	0.78 (0.72–0.84)	0.71 (0.58–0.84)	-0.07
F3	C7	0.80 (0.76–0.84)	0.57 (0.44–0.71)	-0.23
F3	C8	0.84 (0.80–0.87)	0.80 (0.70–0.89)	-0.04
F3	C9	0.88 (0.85–0.92)	0.88 (0.79–0.98)	0.00
F4	C10	0.86 (0.83–0.90)	0.80 (0.69–0.91)	-0.06
F4	C11	0.88 (0.85–0.91)	0.90 (0.83–0.97)	0.02
F4	C12	0.86 (0.82–0.89)	0.92 (0.85–1.00)	0.06
CS	F1	0.80 (0.74–0.85)	0.57 (0.39–0.75)	-0.23
CS	F2	0.69 (0.64–0.75)	0.96 (0.86–1.06)	0.27
CS	F3	0.89 (0.85–0.94)	0.74 (0.62–0.86)	-0.15
CS	F4	0.89 (0.86–0.93)	0.78 (0.67–0.89)	-0.11
SS	S1	0.78 (0.73–0.83)	0.85 (0.77–0.93)	0.07
SS	S2	0.82 (0.78–0.86)	0.88 (0.82–0.95)	0.06
SS	S3	0.77 (0.72–0.82)	0.92 (0.86–0.98)	0.15
SS	S4	0.60 (0.54–0.67)	0.74 (0.61–0.86)	0.14

Est.std = standardised factor loading estimates; CI = confidence interval; F1 = initial stigma subscale; F2 = provider/authority-related stigma subscale; F3 = structural stigma subscale; F4 = enduring stigma subscale; CS = community stigma; SS = self stigma.

C.9 Additional reliability indices

Additional reliability indices from CFA sample

Factor	**Cronbach's alpha**	**Omega**
Community Stigma Scale		
F1 (initial social stigma)	0.74	0.73
F2 (provider/ authority-based stigma)	0.76	0.79
F3 (structural stigma)	0.83	0.84
F4 (enduring social stigma)	0.85	0.86
Self Stigma Scale		
F1 (self stigma)	0.78	0.79

Combined CFA was conducted on a split sample ($N = 504$). Omega represents the hierarchical categorical omega. Alphas and omegas in the range of 0.70–0.95 are typically considered acceptable evidence of reliability.[299]

C.10 Content-validated questions used for regression analysis

Symptom-reporting hesitancy

If you had [X disease/symptoms of X disease], do you think you would feel comfortable telling the following people?

Symptom-reporting question

	Yes (1)	**Probably (2)**	**Unlikely (3)**	**No (4)**
a.1. a healthcare worker*	☐	☐	☐	☐
a.2. a new/[recent sexual$] partner	☐	☐	☐	☐
a.3. a close friend/family member	☐	☐	☐	☐
a.4. your workplace/school/college	☐	☐	☐	☐

Scoring: mean score across four questions. *Notes:* *term differed by context; $specified in mpox survey on recommendation of community co-developers.

Care-seeking hesitancy

If you had symptoms of [X disease] today, would you choose to delay or avoid seeking medical attention for any reason? Options: Yes / Unsure / No / Prefer not to say

Scoring: Yes and unsure grouped for analysis due to low frequencies to form a binary variable.

Acceptance of recovered persons (Adapted Bogardus Social Distance Scale[300])

Please select all that apply below: I would be willing to accept someone who has recently recovered from mpox as…

☐ a new close friend
☐ my doctor
☐ a new neighbour
☐ a visitor in my country/region
Scoring: one point for each, total = sum score.

First question included in Stigma-SCANR Module 1 and latter two in Module 6.

C.11 Draft scale items and reasons for exclusion

Draft scale item distributions and reasons for exclusion

Item: People with [X disease] are…	Mean (SD); median (range)	0	3	0+1	1+2	2+3	Skewness; Kurtosis	Final domain + item no. or reason for exclusion
Draft initial social stigma items								
looked down on	**1.79 (1.11); 2 (0–3)**	**21.27**	**31.61**	**31.21**	**47.12**	**68.79**	**-0.52; -1.06**	**Initial social stigma: C1**
blamed for getting infected	1.44 (1.11); 2 (0–3)	31.11	18.59	43.74	50.3	56.26	-0.11; -1.39	Cross loading in EFA
seen as dirty or immoral	1.32 (1.09); 2 (0–3)	33.2	14.81	49.5	51.99	50.5	0.03; -1.37	Clarity concerns during administration
gossiped about	**2.10 (1.00); 2 (0–3)**	**13.02**	**42.64**	**19.18**	**44.33**	**80.82**	**-0.99; -0.07**	**Initial social stigma: C2**
treated unkindly by the public (including online/on social media)	**1.65 (1.07); 2 (0–3)**	**21.97**	**23.76**	**36.48**	**54.27**	**63.52**	**-0.36; -1.12**	**Initial social stigma: C3**
likely to lose friendships	1.66 (1.06); 2 (0–3)	18.49	26.24	41.65	55.27	58.35	-0.23; -1.17	Low communality and cross loading
at increased risk of physical harm	1.15 (1.05); 1 (0–3)	35.39	12.82	62.52	51.79	37.48	0.37; -1.11	Low communality
Draft provider/authority-related stigma items								
negatively judged by healthcare workers	**0.78 (0.95); 0 (0–3)**	**51.79**	**6.86**	**76.74**	**41.35**	**23.26**	**0.92; -0.33**	**Provider/authority-related stigma: C4**
portrayed negatively in the media	**1.18 (1.12); 1 (0–3)**	**40.06**	**15.61**	**57.95**	**44.33**	**42.05**	**0.31; -1.35**	**Provider/authority-related stigma: C5**
spoken about negatively by religious leaders	0.96 (1.06); 1 (0–3)	47.61	11.33	68.19	41.05	31.81	0.65; -0.96	High correlation with C6 + cross-cultural relevance concerns
spoken about negatively by politicians	**0.92 (1.00); 1 (0–3)**	**45.92**	**8.35**	**69.98**	**45.73**	**30.02**	**0.65; -0.85**	**Provider/authority-related stigma: C6**

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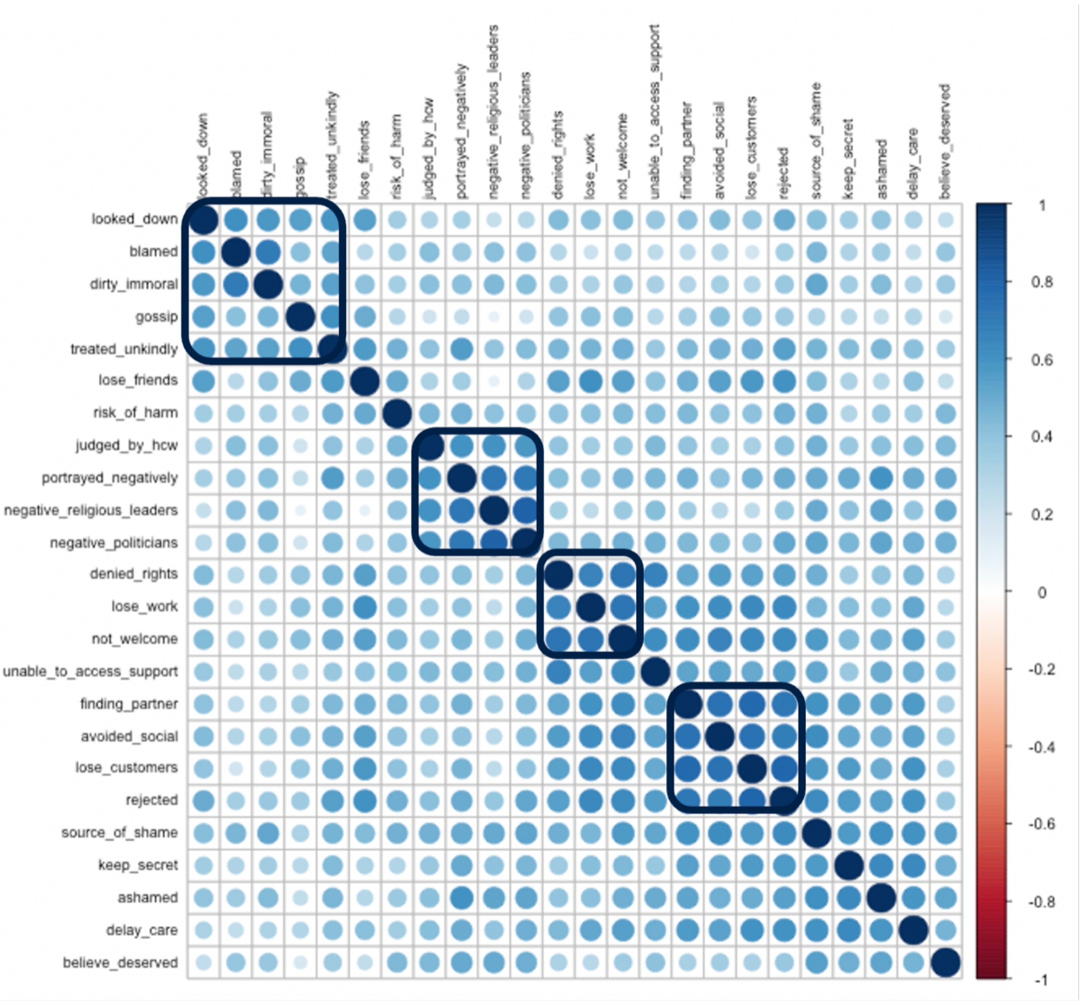
Table C.8 – continued from previous page

Item: People with [X disease] are...	Mean (SD); median (range)	0	3	0+1	1+2	2+3	Skewness; Kurtosis	Final domain + item no. or reason for exclusion
Draft structural stigma items								
denied certain rights	**1.21 (1.08); 1 (0–3)**	**35.39**	**15.01**	**58.75**	**49.6**	**41.25**	**0.29; -1.26**	**Structural stigma: C7**
at risk of losing work or education opportunities	**1.47 (1.07); 2 (0–3)**	**25.05**	**19.28**	**47.51**	**55.67**	**52.49**	**-0.06; -1.25**	**Structural stigma: C8**
not welcome in certain places after recovery	**1.42 (1.07); 2 (0–3)**	**27.04**	**17.99**	**48.81**	**54.97**	**51.19**	**-0.02; -1.27**	**Structural stigma: C9**
unable to access necessary support after recovery	1.09 (1.01); 1 (0–3)	37.18	9.54	63.42	53.28	36.58	0.38; -1.08	Clarity concerns during administration
Draft enduring social stigma items								
likely to have more difficulty finding a partner after recovery	**1.52 (1.10); 2 (0–3)**	**26.14**	**21.37**	**43.14**	**52.49**	**56.86**	**-0.16; -1.30**	**Enduring social stigma: C10**
avoided by neighbours, co-workers, or classmates after recovery	1.54 (1.05); 2 (0–3)	23.06	19.68	42.15	57.26	57.85	-0.21; -1.17	Clarity concerns during administration
at risk of losing customers after recovery if they have a business	**1.55 (1.10); 2 (0–3)**	**25.35**	**22.66**	**41.85**	**51.99**	**58.15**	**-0.20; -1.29**	**Enduring social stigma: C11**
rejected by their community	**1.20 (1.08); 1 (0–3)**	**35.98**	**14.31**	**58.65**	**49.7**	**41.35**	**0.29; -1.26**	**Enduring social stigma: C12**
considered a source of shame for their family*	1.08 (1.04); 1 (0–3)	40.06	10.34	62.03	49.6	37.97	0.38; -1.18	Low communality
Draft self stigma items								
going to try to keep the diagnosis a secret	**1.51 (1.14); 2 (0–3)**	**30.02**	**21.87**	**41.15**	**48.11**	**58.85**	**-0.18; -1.40**	**Self stigma: S1**
ashamed of the diagnosis	**1.47 (1.17); 2 (0–3)**	**32.41**	**23.56**	**44.63**	**44.04**	**55.37**	**-0.08; -1.49**	**Self stigma: S2**
hesitant to seek medical care for their illness	**1.36 (1.12); 2 (0–3)**	**32.5**	**18.09**	**49.4**	**49.4**	**50.6**	**0.04; -1.40**	**Self stigma: S3**
likely to believe they deserved the illness	**0.86 (0.96); 1 (0–3)**	**46.52**	**7.16**	**74.45**	**46.32**	**25.55**	**0.77; -0.55**	**Self stigma: S4**

*Item also included in self stigma analyses due to conceptual overlap. SD = standard deviation. Bold = items included in final scales.

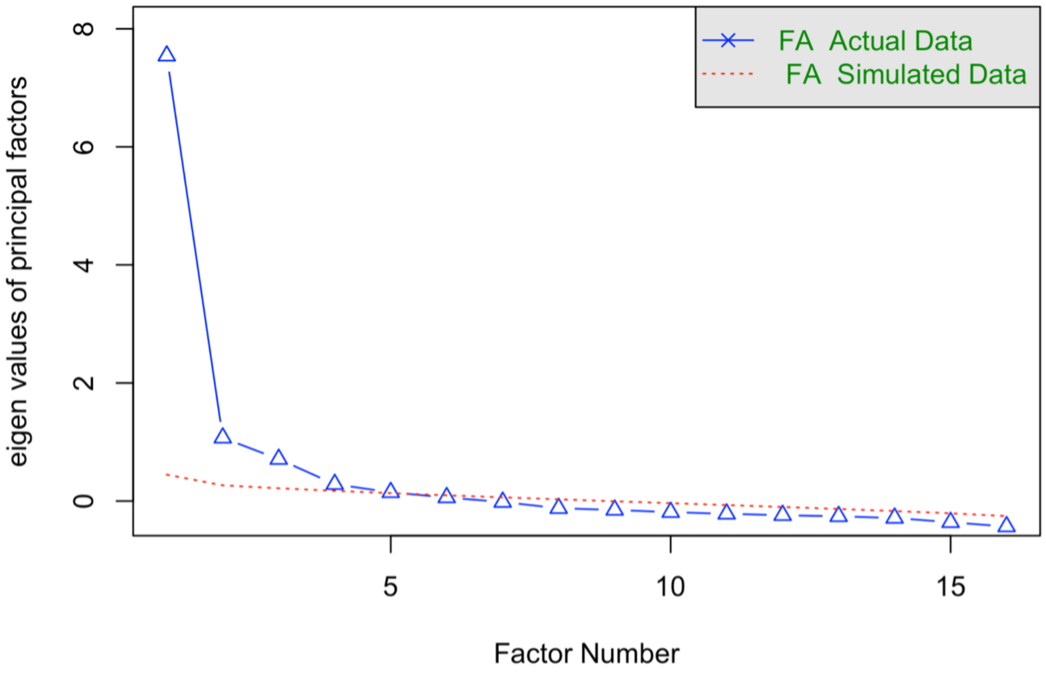
C.12 Correlation matrix



Polychoric correlation matrix. Darker blue = more strongly (positively) correlated. Squares emphasise grouping of community stigma factors. Self stigma items (final 5 items) seen to correlate more broadly with weaker grouping.

C.13 Results of factor number analyses and exploratory factor analysis

For the community stigma scale, a significant Bartlett's test of sphericity ($\chi^2 = 5603.4$, $p < 0.001$, $df = 120$), and 'marvellous' KMO of 0.91, with all item KMO values above 0.83 ('meritorious'), provided evidence that the data were suitable for factor analysis. Parallel analysis suggested 4 factors, while the Empirical Kaiser Criterion suggested 3 factors. The four-factor model had a stable, interpretable factor structure after five runs (Table C.9). This model had better global and local fit indices than the equivalent three factor model and was more consistent with theory (Table C.10).



Parallel Analysis for Factor Retention of Community Stigma items. The analysis recommends retaining the number of factors represented by points that lie above the simulated data line.

Exploratory factor analysis results for the RAPID Stigma Scales

Item	**Statement**	**F1**	**F2**	**F3**	**F4**	h^2	**com**
RAPID Community Stigma Scale							
C1	looked down on	0.63 (0.49–0.75)				0.43	1.01
C2	gossiped about	0.77 (0.66–0.88)				0.52	1.13
C3	treated unkindly by the public (including online/on social media)	0.69 (0.56–0.83)				0.69	1.35
C4	negatively judged by healthcare workers		0.59 (0.45–0.71)			0.35	1.01
C5	portrayed negatively in the media		0.81 (0.68–0.95)			0.63	1.04
C6	spoken about negatively by politicians		0.75 (0.62–0.87)			0.62	1.21
C7	denied certain rights			0.70 (0.52–0.82)		0.55	1.05
C8	at risk of losing work or education opportunities			0.59 (0.44–0.74)		0.58	1.24
C9	not welcome in certain places after recovery			0.85 (0.64–0.99)		0.75	1.02
C10	likely to have more difficulty finding a partner after recovery				0.73 (0.59–0.87)	0.61	1.03
C11	at risk of losing customers after recovery if they have a business				0.96 (0.79–1.06)	0.80	1.01
C12	rejected by their community				0.70 (0.55–0.83)	0.70	1.06

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Table C.9 – continued from previous page

Item	Statement	F1	F2	F3	F4	h^2	com
RAPID Self Stigma Scale							
S1	going to try to keep the diagnosis a secret	0.79 (0.72–0.85)				0.62	1.00
S2	ashamed of the diagnosis	0.71 (0.63–0.78)				0.50	1.00
S3	hesitant to seek medical care for their illness	0.70 (0.61–0.77)				0.48	1.00
S4	likely to believe they deserved the illness	0.56 (0.47–0.64)				0.32	1.00

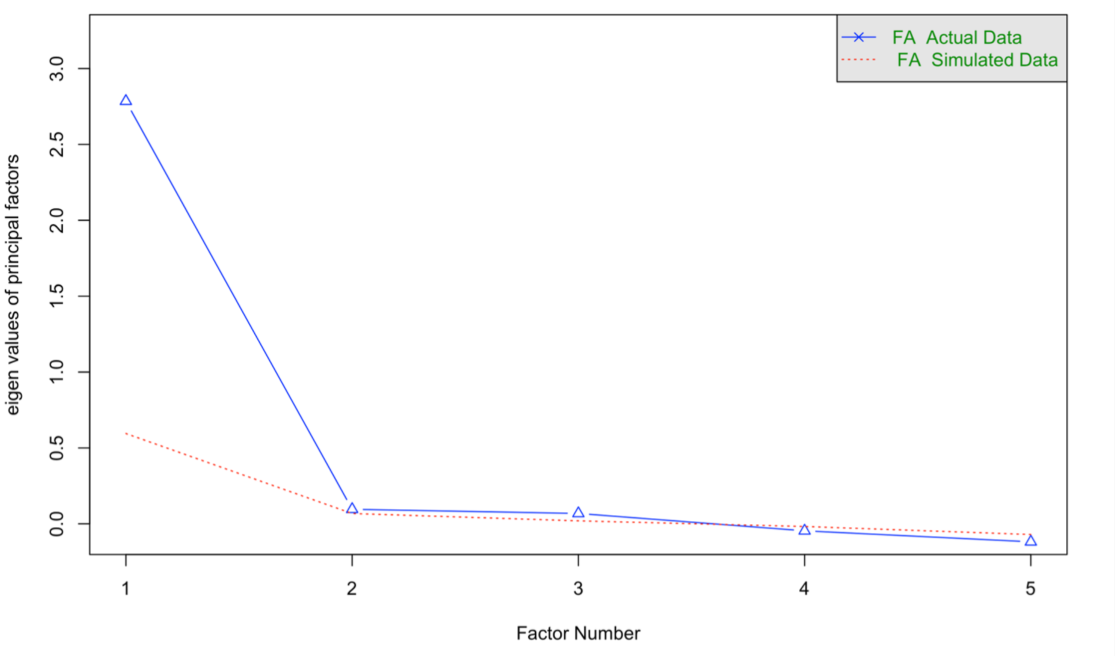
Extraction method: unweighted least squares (ULS) with Promax rotation. Total variance explained = 60.2% (Community) and 47.9% (Self). No residuals > 0.1 for either scale. $N = 503$ (Community), $N = 504$ (Self). Blank cells indicate loadings < 0.30. Items scored on a 4-point Likert scale (3 = Yes, 2 = Probably, 1 = Unlikely, 0 = No). h^2 = item communality (variance explained); com = complexity. 95% confidence intervals were obtained via bootstrapping ($n = 1000$) with Procrustes rotation to align factors across resamples.

Comparison of 4-factor and 3-factor Community EFA

Metric	4-Factor Model	3-Factor Model
TLI	0.979	0.877
RMSEA	0.0415	0.1018
RMSR	0.015	0.037
BIC	-104.487	-0.299
Residuals > 0.1	None	Two
Cumulative Var	60.2%	55.7%

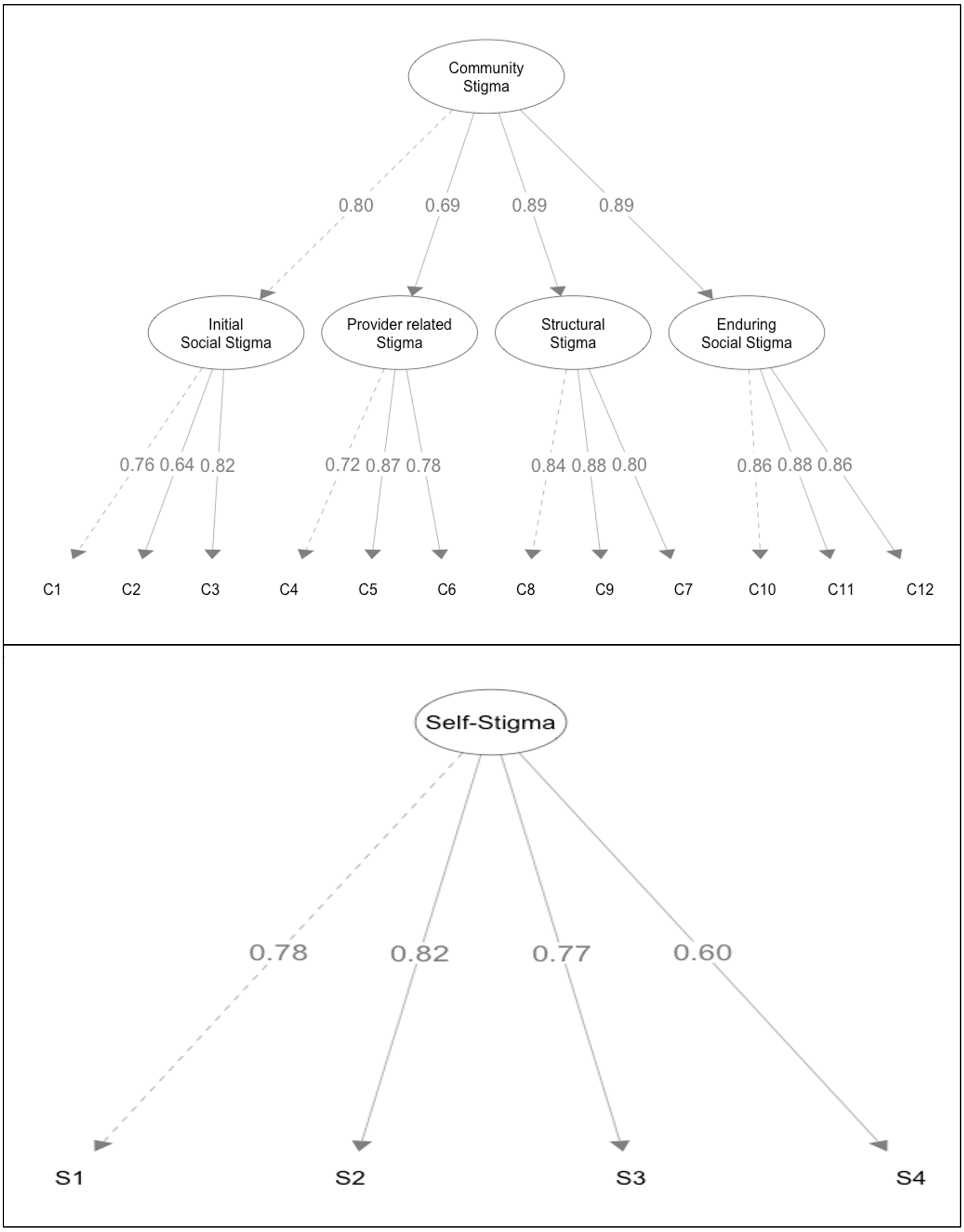
TLI = Tucker-Lewis Index; RMSEA = Root Mean Square Error of Approximation; RMSR = Root Mean Square Residual; BIC = Bayesian Information Criterion; Residuals > 0.1 = number of residuals with an absolute value greater than 0.1; Cumulative Var = cumulative percentage of variance explained by the factors.

For the self stigma scale parallel analysis and the Empirical Kaiser Criterion suggested a single factor. The unidimensional model had a stable, interpretable factor structure after two runs (Table C.9).



Parallel Analysis for Factor Retention of Self Stigma items

C.14 Model path diagrams



Path diagrams for Community Stigma and Self Stigma Scales. Numbers show standardised loadings. C1-12 and S1-4 are final item numbers.

C.15 Community stigma model fit comparisons

Community stigma model fit comparisons using CFA

Index	Unidimensional Model	Multidimensional 4 Factor Model	Second Order 4 Factor Model	Second Order 3 Factor Model	Bifactor Model*
CFI (scaled)	0.890	0.984	**0.987**	0.961	NA
TLI (scaled)	0.866	0.979	**0.982**	0.950	NA
RMSEA (90% CI)	0.141 (0.131–0.151)	0.038 (0.023–0.051)	**0.037 (0.022–0.050)**	0.076 (0.066–0.088)	0.020 (0.000–0.040)
SRMR	0.094	0.040	**0.040**	0.053	0.027
Chi-Square (scaled)	894.009	167.561	**153.194**	346.508	NA
Degrees of freedom	54.000	48.000	**50.000**	51.000	32.000
p-value (scaled)	0.000	0.000	**0.000**	0.000	NA

CFI = Comparative Fit Index; TLI = Tucker-Lewis Index; RMSEA = Root Mean Square Error of Approximation; CI = Confidence interval (90% CI reported for RMSEA as per structural equation modelling convention); SRMR = Standardised Root Mean Square Residual.
*Model's covariance matrix could not be inverted suggesting a model identification issue. Final selected model (second order 4 factor) in bold.

C.16 Model fit indices for each site

Model fit indices by site

Fit Measure	**Uganda (Ebola) N = 302**	**UK (mpox) N = 406**	**Bangladesh (Nipah) N = 300**
Community Stigma Scale			
CFI (scaled)	0.98	0.98	0.97
TLI (scaled)	0.97	0.98	0.97
RMSEA (90% CI)	0.04 (0.01–0.05)	0.06 (0.04–0.07)	0.04 (0.02–0.06)
SRMR	0.05	0.04	0.07
Chi-Square (scaled)	114.19	197.29	120.68
Degrees of freedom	50	50	50
p-value (scaled)	<0.01	<0.01	<0.01
Self Stigma Scale			
CFI (scaled)	0.99	1.00	1.00
TLI (scaled)	0.96	1.00	1.01
RMSEA (90% CI)	0.05 (0.00–0.13)	0.00 (0.00–0.08)	0.00 (0.00–0.02)
SRMR	0.04	0.01	0.01
Chi-Square (scaled)	4.97	2.44	0.41
Degrees of freedom	2	2	2
p-value (scaled)	0.08	0.30	0.82

CFI = Comparative Fit Index; TLI = Tucker-Lewis Index; RMSEA = Root Mean Square Error of Approximation; CI = Confidence interval (90% CI reported for RMSEA as per structural equation modelling convention); SRMR = Standardised Root Mean Square Residual.

C.17 Item- and factor-level statistics by study cohort

Item- and factor-level statistics for each study cohort and combined

Item	**mean (SD); median (range)**			
People who have [X disease] are...	**Uganda (Ebola)**	**UK (mpox)**	**Bangladesh (Nipah)**	**Combined**
RAPID Community Stigma Scale				
F1: Initial social stigma	2.07 (0.85); 2.33 (0–3)	1.94 (0.68); 2 (0–3)	1.50 (0.98); 1.67 (0–3)	1.85 (0.86); 2 (0–3)
C1: looked down on	2.11 (1.17); 3 (0–3)	1.89 (0.79); 2 (0–3)	1.34 (1.27); 1 (0–3)	1.79 (1.11); 2 (0–3)
C2: gossiped about	2.34 (1.00); 3 (0–3)	2.06 (0.77); 2 (0–3)	1.92 (1.22); 2 (0–3)	2.10 (1.00); 2 (0–3)
C3: treated unkindly by the public (including online/on social media)	1.76 (1.16); 2 (0–3)	1.88 (0.81); 2 (0–3)	1.24 (1.17); 1 (0–3)	1.65 (1.07); 2 (0–3)
F2: Provider/authority-related stigma	0.82 (0.84); 0.67 (0–3)	1.38 (0.74); 1.33 (0–3)	0.53 (0.73); 0 (0–3)	0.96 (0.84); 1 (0–3)
C4: negatively judged by healthcare workers	0.67 (1.01); 0 (0–3)	1.03 (0.82); 1 (0–3)	0.56 (0.99); 0 (0–3)	0.78 (0.95); 0 (0–3)
C5: portrayed negatively in the media	1 (1.15); 1 (0–3)	1.77 (0.91); 2 (0–3)	0.55 (0.94); 0 (0–3)	1.18 (1.12); 1 (0–3)
C6: spoken about negatively by politicians	0.79 (1.07); 0 (0–3)	1.33 (0.92); 1 (0–3)	0.50 (0.80); 0 (0–3)	0.92 (1.00); 1 (0–3)
F3: Structural stigma	1.76 (0.99); 2 (0–3)	1.34 (0.72); 1.33 (0–3)	1.00 (0.94); 1 (0–3)	1.36 (0.92); 1.33 (0–3)
C7: denied certain rights	1.53 (1.21); 2 (0–3)	1.13 (0.86); 1 (0–3)	0.99 (1.15); 0 (0–3)	1.21 (1.08); 1 (0–3)
C8: at risk of losing work or education opportunities	2.05 (1.08); 2 (0–3)	1.41 (0.80); 1 (0–3)	0.96 (1.08); 0 (0–3)	1.47 (1.07); 2 (0–3)
C9: not welcome in certain places after recovery	1.71 (1.21); 2 (0–3)	1.48 (0.82); 2 (0–3)	1.05 (1.12); 1 (0–3)	1.42 (1.07); 2 (0–3)

Continued on next page

Table C.13 – continued from previous page

People who have [X disease] are. . .	Uganda (Ebola)	UK (mpox)	Bangladesh (Nipah)	Combined
F4: Enduring social stigma	1.97 (0.96); 2 (0–3)	1.56 (0.70); 1.67 (0–3)	0.68 (0.82); 0.33 (0–3)	1.42 (0.97); 1.67 (0–3)
C10: likely to have more difficulty finding a partner after recovery	1.96 (1.14); 2 (0–3)	1.72 (0.82); 2 (0–3)	0.81 (1.04); 0 (0–3)	1.52 (1.10); 2 (0–3)
C11: at risk of losing customers after recovery if they have a business	2.20 (1.07); 3 (0–3)	1.64 (0.79); 2 (0–3)	0.78 (1.03); 0 (0–3)	1.55 (1.10); 2 (0–3)
C12: rejected by their community	1.75 (1.23); 2 (0–3)	1.33 (0.79); 1 (0–3)	0.46 (0.83); 0 (0–3)	1.20 (1.08); 1 (0–3)
Overall	1.66 (0.72); 1.83 (0–3)	1.55 (0.60); 1.58 (0–3)	0.93 (0.63); 0.83 (0–3)	1.40 (0.72); 1.42 (0–3)
RAPID Self Stigma Scale				
S1: going to try to keep the diagnosis a secret	1.64 (1.24); 2 (0–3)	2 (0.74); 2 (0–3)	0.71 (0.84); 0 (0–3)	1.51 (1.14); 2 (0–3)
S2: ashamed of the diagnosis	1.36 (1.26); 1 (0–3)	2.08 (0.78); 2 (0–3)	0.70 (1.03); 0 (0–3)	1.47 (1.17); 2 (0–3)
S3: hesitant to seek medical care for their illness	1.57 (1.25); 2 (0–3)	1.67 (0.82); 2 (0–3)	0.74 (1.07); 0 (0–3)	1.36 (1.12); 2 (0–3)
S4: likely to believe they deserved the illness	0.64 (0.94); 0 (0–3)	1.17 (0.82); 1 (0–3)	0.73 (1.07); 0 (0–3)	0.86 (0.96); 1 (0–3)
Overall	1.30 (0.80); 1.50 (0–3)	1.73 (0.61); 1.75 (0–3)	0.66 (1.03); 0.38 (0–3)	1.30 (0.85); 1.50 (0–3)

C.18 Residual correlation matrices

Residual Correlation Matrix of the Community Stigma Confirmatory Factor Analysis Model

	C1	**C2**	**C3**	**C4**	**C5**	**C6**	**C8**	**C9**	**C7**	**C10**	**C11**	**C12**
C1	0.00	0.06	-0.05	-0.04	-0.01	-0.08	0.01	-0.00	0.04	-0.00	-0.04	0.06
C2	0.06	0.00	0.02	-0.06	-0.04	-0.14	0.04	0.02	0.05	-0.02	-0.06	-0.09
C3	-0.05	0.02	0.00	0.00	0.10	0.00	-0.00	-0.01	-0.03	-0.02	-0.03	0.07
C4	-0.04	-0.06	0.00	0.00	-0.01	-0.01	-0.03	0.04	0.09	0.03	-0.04	0.01
C5	-0.01	-0.04	0.10	-0.01	0.00	0.01	-0.09	-0.01	-0.03	0.01	-0.03	0.03
C6	-0.08	-0.14	0.00	-0.01	0.01	0.00	-0.02	0.02	-0.03	0.01	-0.05	0.09
C8	0.01	0.04	-0.00	-0.03	-0.09	-0.02	0.00	-0.03	0.01	0.02	0.03	0.02
C9	-0.00	0.02	-0.01	0.04	-0.01	0.02	-0.03	0.00	0.02	0.01	-0.01	-0.01
C7	0.04	0.05	-0.03	0.09	-0.03	-0.03	0.01	0.02	0.00	-0.04	-0.03	-0.05
C10	-0.00	-0.02	-0.02	0.03	0.01	0.01	0.02	0.01	-0.04	0.00	0.03	-0.06
C11	-0.04	-0.06	-0.03	-0.04	-0.03	-0.05	0.03	-0.01	-0.03	0.03	0.00	0.00
C12	0.06	-0.09	0.07	0.01	0.03	0.09	0.02	-0.01	-0.05	-0.06	0.00	0.00

Residual Correlation Matrix of the Self Stigma Confirmatory Factor Analysis Model

	S1	**S2**	**S3**	**S4**
S1	0.00	-0.00	0.01	-0.02
S2	-0.00	0.00	-0.01	0.03
S3	0.01	-0.01	0.00	-0.01
S4	-0.02	0.03	-0.01	0.00

C.19 Results of multiple regression analyses for external construct validity hypothesis testing

Hypothesis 1: Higher community stigma score is associated with higher symptom-reporting hesitancy.

Results of multiple linear regression testing hypothesis 1

Predictors (independent variable and covariates)	β Coefficient Estimate	95% Confidence Interval	Standard Error	t-value	p-value
Community stigma score	**0.21**	**[0.15, 0.27]**	**0.03**	**6.66**	**<0.001**
Age	<0.01	[-0.00, 0.00]	0.00	-0.05	0.96
Gender (reference: Man)					
Woman	<0.01	[-0.08, 0.08]	0.04	0.01	0.99
Other	-0.12	[-0.30, 0.06]	0.09	-1.34	0.18
Disease (reference: Nipah virus disease)					
Ebola disease	0.03	[-0.09, 0.15]	0.06	0.51	0.61
Mpox	0.32	[0.22, 0.42]	0.05	5.87	<0.001
Nature of residence (reference: Urban)					
Rural	-0.05	[-0.13, 0.03]	0.04	-1.26	0.21
Clinical care provider status (reference: No)					
Yes	-0.10	[-0.20, -0.00]	0.05	-1.82	0.07
Outbreak support staff status (reference: No)					
Yes	-0.11	[-0.25, 0.03]	0.07	-1.65	0.10
Close relationship with someone who had illness (reference: No)					
Yes	0.06	[-0.04, 0.16]	0.05	1.16	0.25
Prefer not to say	-0.22	[-0.61, 0.17]	0.20	-1.07	0.29
Personal experience of illness of concern (reference: No)					
Yes	-0.03	[-0.7, 0.64]	0.34	-0.08	0.94
Unsure	-0.02	[-0.29, 0.25]	0.14	-0.14	0.89
Prefer not to say	-0.16	[-0.63, 0.31]	0.24	-0.67	0.50
Self-reported understanding of illness (reference: Heard of it but don't know details)					
Understand basics	0.06	[-0.02, 0.14]	0.04	1.31	0.19
Know more than basics	0.13	[-0.01, 0.27]	0.07	1.87	0.06
Intercept					
Intercept (α)	1.24	[1.06, 1.42]	0.09	13.60	<0.001

Hypothesis 2: Higher self stigma score is associated with higher symptom-reporting hesitancy.

Results of multiple linear regression testing hypothesis 2

Predictors (independent variable and covariates)	**β Coefficient Estimate**	**95% Confidence Interval**	**Standard Error**	**t-value**	**p-value**
Self stigma score	**0.19**	**[0.13, 0.24]**	**0.03**	**6.82**	**<0.001**
Age	<0.01	[-0.00, 0.00]	0.00	0.04	0.97
Gender (reference: Man)					
Woman	<0.01	[-0.09, 0.09]	0.05	-0.01	0.99
Other	-0.11	[-0.29, 0.07]	0.09	-1.19	0.24
Disease (reference: Nipah)					
Ebola disease	0.06	[-0.06, 0.19]	0.06	1.04	0.30
Mpox	0.26	[0.15, 0.37]	0.06	4.54	<0.001
Nature of Residence (reference: Urban)					
Rural	-0.05	[-0.13, 0.04]	0.04	-1.12	0.27
Clinical care provider status (reference: No)					
Yes	-0.12	[-0.23, -0.02]	0.05	-2.24	0.03
Outbreak support staff status (reference: No)					
Yes	-0.10	[-0.22, 0.03]	0.07	-1.45	0.15
Close relationship with someone who had illness (reference: No)					
Yes	0.07	[-0.03, 0.18]	0.05	1.35	0.18
Prefer not to say	-0.19	[-0.59, 0.20]	0.20	-0.95	0.34
Personal experience of illness of concern (reference: No)					
Yes	-0.01	[-0.68, 0.66]	0.34	-0.02	0.99
Unsure	-0.04	[-0.30, 0.23]	0.13	-0.27	0.79
Prefer not to say	-0.12	[-0.60, 0.36]	0.24	-0.49	0.62
Self-reported understanding of illness (reference: Heard of it but don't know details)					
Understand basics	0.05	[-0.04, 0.14]	0.05	1.07	0.29
Know more than basics	0.11	[-0.03, 0.24]	0.07	1.59	0.11
Intercept					
Intercept (α)	1.30	[1.13, 1.47]	0.09	14.71	<0.001

Hypothesis 3: Higher community stigma score is associated with higher care-seeking hesitancy.

Results of multiple linear regression testing hypothesis 3

Predictors (independent variable and covariates)	Odds Ratio	95% Confidence Interval	z-statistic	p-value
Community stigma score	**1.63**	**[1.22, 2.19]**	**3.31**	**<0.001**
Age	0.99	[0.98, 1.01]	-0.71	0.48
Gender (reference: Man)				
Woman	1.03	[0.68, 1.57]	0.16	0.88
Other	0.46	[0.16, 1.08]	-1.65	0.10
Disease (reference: Nipah)				
Ebola disease	1.37	[0.76, 2.48]	1.03	0.30
Mpox	1.33	[0.79, 2.28]	1.06	0.29
Nature of residence (reference: Urban)				
Rural	0.79	[0.54, 1.16]	-1.19	0.23
Clinical care provider status (reference: No)				
Yes	0.48	[0.28, 0.78]	-2.85	0.004
Outbreak support staff status (reference: No)				
Yes	0.40	[0.18, 0.80]	-2.42	0.02
Close relationship with someone who had illness (reference: No)				
Yes	0.69	[0.43, 1.11]	-1.51	0.13
Prefer not to say	0.30	[0.02, 1.82]	-1.08	0.28
Personal experience of illness of concern (reference: No)				
Yes	2.07	[1.17, 3.57]	2.55	0.01
Unsure	3.23	[1.14, 8.52]	2.32	0.02
Prefer not to say	1.72	[0.09, 12.24]	0.47	0.64
Self-reported understanding of illness (reference: Heard of it but don't know details)				
Understand basics	0.51	[0.34, 0.76]	-3.26	0.001
Know more than basics	0.62	[0.34, 1.13]	-1.54	0.12
Intercept				
Intercept (α)	0.19	[0.08, 0.44]	-3.87	<0.001

Hypothesis 4: Higher self stigma score is associated with higher care-seeking hesitancy.

Results of multiple linear regression testing hypothesis 4

Predictors (independent variable and covariates)	Odds Ratio (OR)	95% Confidence Interval (OR)	z-statistic	p-value
Self stigma score	**1.71**	**[1.33, 2.21]**	**4.15**	**<0.001**
Age	1.00	[0.98, 1.01]	-0.60	0.55
Gender (reference: Man)				
Woman	1.04	[0.68, 1.57]	0.17	0.87
Other	0.48	[0.17, 1.13]	-1.57	0.12
Disease (reference: Nipah)				
Ebola disease	1.40	[0.79, 2.51]	1.15	0.25
Mpox	1.08	[0.63, 1.88]	0.27	0.79
Nature of residence (reference: Urban)				
Rural	0.82	[0.56, 1.20]	-1.02	0.31
Clinical care provider status (reference: No)				
Yes	0.44	[0.26, 0.73]	-3.09	0.002
Outbreak support staff status (reference: No)				
Yes	0.42	[0.19, 0.84]	-2.31	0.02
Close relationship with someone who had illness (reference: No)				
Yes	0.72	[0.44, 1.15]	-1.36	0.17
Prefer not to say	0.32	[0.02, 1.91]	-1.03	0.30
Personal experience of illness of concern (reference: No)				
Yes	2.22	[1.25, 3.84]	2.79	0.005
Unsure	3.14	[1.11, 8.26]	2.27	0.02
Prefer not to say	1.95	[0.10, 14.46]	0.57	0.57
Self-reported understanding of illness (reference: Heard of it but don't know details)				
Understand basics	0.49	[0.33, 0.74]	-3.40	0.001
Know more than basics	0.60	[0.33, 1.10]	-1.63	0.10
Intercept				
Intercept (α)	0.19	[0.08, 0.44]	-3.91	<0.001

Hypothesis 5: Higher community stigma score is associated with lower acceptance of recovered persons.

Results of multiple linear regression testing hypothesis 5

Predictors (independent variable and covariates)	β Coefficient Estimate	95% Confidence Interval	Standard Error	t-value	p-value
Community stigma score	**-0.22**	**[-0.32, -0.12]**	**0.05**	**-4.54**	**<0.001**
Age	<0.01	[-0.00, 0.01]	0.00	1.48	0.14
Gender (reference: Man)					
Woman	-0.04	[-0.18, 0.10]	0.07	-0.54	0.59
Other	0.55	[0.25, 0.85]	0.15	3.57	<0.001
Disease (reference: Nipah virus disease)					
Ebola disease	-0.26	[-0.45, -0.06]	0.10	-2.61	0.01
Mpox	-0.34	[-0.52, -0.17]	0.09	-3.94	<0.001
Nature of Residence (reference: Urban)					
Rural	-0.12	[-0.25, 0.01]	0.07	-1.76	0.08
Clinical care provider status (reference: No)					
Yes	-0.13	[-0.30, 0.03]	0.09	-1.56	0.12
Outbreak support staff status (reference: No)					
Yes	0.04	[-0.16, 0.24]	0.10	0.37	0.71
Close relationship with someone who had illness (reference: No)					
Yes	-0.01	[-0.17, 0.15]	0.08	-0.15	0.88
Prefer not to say	-0.09	[-0.71, 0.53]	0.32	-0.30	0.77
Personal experience of illness of concern (reference: No)					
Yes	-3.36	[-3.58, -3.15]	0.11	-30.85	<0.001
Unsure	0.20	[-0.23, 0.64]	0.22	0.91	0.36
Prefer not to say	-0.19	[-0.99, 0.60]	0.40	-0.48	0.63
Self-reported understanding of illness (reference: Heard of it but don't know details)					
Understand basics	0.07	[-0.07, 0.21]	0.07	1.03	0.30
Know more than basics	0.12	[-0.09, 0.33]	0.11	1.13	0.26
Intercept					
Intercept (α)	3.81	[3.53, 4.10]	0.14	26.4	<0.001

Hypothesis 6: Higher community stigma score is associated with higher self stigma.

Results of multiple linear regression testing hypothesis 6

Predictors (independent variable and covariates)	**Beta Coefficient (β)**	**95% Confidence Interval (β)**	**Standard Error**	**t-value**	**p-value**
Community stigma score	**0.72**	**[0.66, 0.77]**	**0.03**	**26.02**	**<0.001**
Age	<0.01	[-0.01, 0.00]	0.00	-1.43	0.15
Gender (reference: Man)					
Woman	<0.01	[-0.08, 0.08]	0.04	-0.04	0.97
Other	-0.06	[-0.23, 0.11]	0.09	-0.70	0.48
Disease (reference: Nipah)					
Ebola disease	0.06	[-0.05, 0.17]	0.06	1.06	0.29
Mpox	0.50	[0.40, 0.60]	0.05	10.01	<0.001
Nature of residence (reference: Urban)					
Rural	-0.05	[-0.13, 0.02]	0.04	-1.34	0.18
Clinical care provider status (reference: No)					
Yes	0.17	[0.07, 0.26]	0.05	3.41	0.001
Outbreak support staff status (reference: No)					
Yes	-0.06	[-0.18, 0.05]	0.06	-1.05	0.29
Close relationship with someone who had illness (reference: No)					
Yes	-0.10	[-0.19, -0.01]	0.05	-2.10	0.04
Prefer not to say	-0.05	[-0.41, 0.30]	0.18	-0.30	0.77
Personal experience of illness of concern (reference: No)					
Yes	-0.09	[-0.21, 0.03]	0.06	-1.45	0.15
Unsure	0.06	[-0.19, 0.31]	0.13	0.50	0.62
Prefer not to say	-0.35	[-0.80, 0.10]	0.23	-1.53	0.13
Self-reported understanding of illness (reference: Heard of it but don't know details)					
Understand basics	0.10	[0.02, 0.18]	0.04	2.44	0.02
Know more than basics	0.15	[0.03, 0.27]	0.06	2.51	0.01
Intercept					
Intercept (α)	0.12	[-0.04, 0.28]	0.08	1.47	0.14

C.20 Stigma-SCANR tool and note for end-users

Notes for researchers and practitioners interested in these tools

The cross-outbreak stigma assessment tools consist of two main components:

1) the (Re)-emerging and epidemic-Prone Infectious Diseases (RAPID) Stigma Scales: a brief, transferable set of stigma scales, and
2) the Stigma Survey and Community-based Assessment for New and Re-emerging outbreaks (Stigma-SCANR): an in-depth, modular survey.

The best tool to use depends on your objectives. If your objective is:

A) rapid identification and repeat evaluation of stigma at the community-level during an outbreak → the RAPID Stigma Scales will be more helpful

B) in-depth understanding of causes, manifestations and impacts of this stigma → the Stigma-SCANR modules will be more helpful

You can also choose to use only one RAPID scale or certain modules from within these tools.

We encourage you to locally pilot the tools for your specific context before use and adapt them if necessary. We are available to provide support with this process. The tools are designed to be applicable to a general population sample (provided respondents are aware of the disease), as well as people recovered from the disease, affected family members or friends, healthcare workers, and other outbreak responders. We recommend considering which sample would be most appropriate for your setting, and choosing an adequately powered sample size and sampling strategy that optimises representativeness. We also strongly recommend ensuring that psychosocial support or referral mechanisms are available before using these tools with affected individuals. **Please note that the RAPID Scales and Stigma-SCANR modules 1-4 and 7 are designed to assess community-level norms, rather than individual attitudes or experiences. These will therefore need further adaptation and validation for individual-level assessment.**

The details of the psychometric validation of the RAPID scales are available from the Lancet Infectious Diseases *here* and a corresponding publication for the more detailed Stigma-SCANR is available *here*.

A final note that the RAPID scales subdomains have been kept short (3-4 items each) to minimise the length, however, this means that if you find one of the items does not perform as expected, there may only be two items left in that subdomain. In this case you may wish to explore grouping subdomains (for example, initial and enduring social stigma) or only using some items at the community stigma scale level rather than at a subscale level. We would be happy to provide further guidance on this as needed.

Please contact Dr Amy Paterson (*amy.paterson@ndm.ox.ac.uk*), with any questions or for support in using these tools.

Survey instructions

*Note for end-users: Where an item or wording is dependent on context, disease, or mode of administration it is written in [square brackets]. Branching logic is indicated by symbols (e.g. *,#). These instructions may need to be adapted based on the context and ethics committee requirements.*

Thank you for your interest in this survey on [X disease] stigma. This survey is run by researchers from [X institution].

[X disease] stigma happens when people look down on someone or treat them unkindly because they associate them with [X disease].

Some important details before you begin:

1. We would like people to answer this survey if they are 18 years or older and have heard about [X disease]. You don't need to have had personal experience of [X disease] to take part in the survey. [adapt according to eligibility criteria]
2. It is voluntary to do the survey.
3. It usually takes about [X minutes] to complete.
4. Your responses will be kept anonymous. We will not ask for your name or contact details.
5. Although it will not immediately benefit you, taking part in the survey will help us to reduce stigma and assist people who feel stigmatised in the future.
6. There is a risk that some of the questions remind you of difficult personal experiences. If this is the case for you, you can take a break or stop the survey. [You can access resources for psychological or social support here: [add link] OR We can refer you for psychological or social support].
7. Submitting the survey will be taken as permission to store and use your anonymous responses for this research. This research will be published in an open-access journal.
8. Please only take the survey once.
9. This research has received ethics clearance from [X ethical board] (reference number: [XXXX]).

If you have any questions or concerns about this survey please speak to [add PI and contact details]. We will acknowledge your question or concern within 10 working days. You can also contact the Chair of the Research Ethics Committee at [X address]

Are you happy to proceed? Yes/No

Background details

[for adaptation to specific outbreak context]

- Age: ___ years
- Residential region:
- Nature of residence: urban (city/large town)/rural (small town/village)
- Sex assigned at birth: male/female/other/prefer not to say
- Gender identity: woman/man/[non-binary]/other: please specify/prefer not to say
- [Sexual orientation: straight/gay/lesbian/bisexual/asexual/other: please specify/prefer not to say]
- [Have you received an [X disease] vaccine? yes/no/unsure/prefer not to say]
- Are you a healthcare worker? Yes*/No$^{\#}$
- $^{\#}$Have you done work related to an infectious disease outbreak? Yes*/No
- *Have you been involved in responding to the [X disease] outbreak? Yes/No
- How would you rate your understanding of [X disease]?
  - ○ Never heard of it [end survey]
  - ○ Heard of it but don't know many details
  - ○ Understand the basics (e.g. typical symptoms)
  - ○ Know more than the basics (e.g. epidemiology)
- Has anyone close to you had [X disease]? Yes*/No/Prefer not to say
- *Have you lost anyone close to you to [X disease]? Yes/No/Prefer not to say

The Stigma Survey and Community-based Assessment for New and Re-emerging outbreaks (Stigma-SCANR)

Module 1 is about stigma and care-seeking:

In your opinion:

1a. Which of the following concerns are reasons someone with [X disease] symptoms would avoid seeking medical attention? (select all that apply)

☐ how their family members might respond

☐ how friends might respond

☐ how the public might respond

☐ how the government might respond

☐ concerns about losing accommodation

☐ concerns about losing work or education opportunities

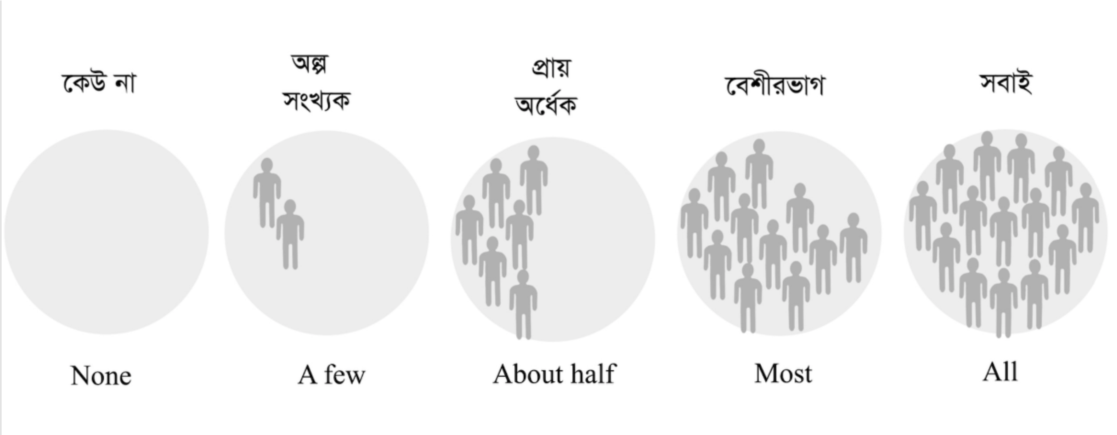
☐ concerns about unkind treatment at the healthcare facility

☐ concerns about their name being linked to the disease

☐ concerns about feeling ashamed

☐ concerns that nothing can be done to help

1b. If you had symptoms of [X disease] today, would you choose to delay or avoid seeking medical attention for any reason? Yes/No/Unsure/Prefer not to say



Visual aid for module 2-4. English and Bengali version

Module 2 is about underlying beliefs and feelings:

Please answer the following questions based on what you have experienced, seen, or heard in your community [define time period as appropriate].

In this survey ‘your community’ means all the people you regularly interact with.

Imagine it is known that someone in your community has just been diagnosed with [X disease].

2a. How many people would believe that the person with [X disease]...

		None	**A few**	**About half**	**Most**	**All**
2a.1.	should be supported	o	o	o	o	o
2a.2.	is to blame for getting [X disease]	o	o	o	o	o
2a.3.	is immoral or sinful	o	o	o	o	o
2a.4.	is dirty	o	o	o	o	o
2a.5.	is cursed [or bewitched]	o	o	o	o	o
2a.6.	is dangerous	o	o	o	o	o

2b. How many people would feel…

	None	**A few**	**About half**	**Most**	**All**
2b.1. Sympathy for the person with [X disease]	o	o	o	o	o
2b.2. Disapproving of the person (look down on them)	o	o	o	o	o
2b.3. Afraid of the person	o	o	o	o	o
2b.4. Disgusted by the person	o	o	o	o	o
2b.5. Angry with the person	o	o	o	o	o

Module 3 is about anticipated social stigma manifestations:

3a. How many of the following people might negatively judge the person because they have [X disease]?

	None	**A few**	**About half**	**Most**	**All**
3a.1. [Casual/potential sexual partners]	o	o	o	o	o
3a.2. [Established] partners/spouses	o	o	o	o	o
3a.3. The person's family members	o	o	o	o	o
3a.4. The person's friends	o	o	o	o	o
3a.5. [The person's neighbours]	o	o	o	o	o
3a.6. The person's co-workers/classmates	o	o	o	o	o
3a.7. General public	o	o	o	o	o

3b. How many of the following people might talk badly about the person known to have [X disease] (including insulting language by message or social media)?

	None	**A few**	**About half**	**Most**	**All**
3b.1. [Casual/potential sexual partners]	o	o	o	o	o
3b.2. [Established] partners/spouses	o	o	o	o	o
3b.3. The person's family members	o	o	o	o	o
3b.4. The person's friends	o	o	o	o	o
3b.5. [The person's neighbours]	o	o	o	o	o
3b.6. The person's co-workers/classmates	o	o	o	o	o
3b.7. General public	o	o	o	o	o
3b.8. Healthcare workers[1]	o	o	o	o	o
3b.9. Religious/community leaders	o	o	o	o	o
3b.10. Politicians	o	o	o	o	o
3b.11. The media/journalists	o	o	o	o	o

[1] including those working in clinics, GP practices, ambulances, hospitals, and treatment units

3c. How many of the following people might physically harm or threaten to harm the person with [X disease] or their property (including once recovered)?

	None	**A few**	**About half**	**Most**	**All**
3c.1. [Casual/potential sexual partners]	o	o	o	o	o
3c.2. [Established] partners/spouses	o	o	o	o	o
3c.3. The person's family members	o	o	o	o	o
3c.4. The person's friends	o	o	o	o	o
3c.5. [The person's neighbours]	o	o	o	o	o
3c.6. The person's co-workers/classmates	o	o	o	o	o
3c.7. General public	o	o	o	o	o

3d. How many of the following people might avoid a person known to have recently recovered from [X disease]?

		None	A few	About half	Most	All
3d.1.	[Casual/potential sexual partners]	○	○	○	○	○
3d.2.	[Established] partners/spouses	○	○	○	○	○
3d.3.	The person's family members	○	○	○	○	○
3d.4.	The person's friends	○	○	○	○	○
3d.6.	The person's co-workers/classmates	○	○	○	○	○
3d.7.	General public	○	○	○	○	○

3e. How many people in the community might tell others about a person's [X disease] diagnosis without their permission?

None	A few	About half	Most	All
○	○	○	○	○

3f. If people in your community heard that a hairdresser had recently recovered from [X disease] how many might still get their hair cut by them?

None	A few	About half	Most	All
○	○	○	○	○

Module 4 is about anticipated structural stigma:

In your opinion/experience:

4. How many of the following places/institutions might disadvantage or exclude people known to have recently recovered from [X disease]?

	None	**A few**	**About half**	**Most**	**All**
4.1. Government facilities	o	o	o	o	o
4.2. Workplaces	o	o	o	o	o
4.3. Schools or colleges	o	o	o	o	o
4.4. Healthcare facilities (e.g. clinics or hospitals)	o	o	o	o	o
4.5. Community gatherings/groups	o	o	o	o	o
4.6. Businesses (e.g. shops/bars/gyms)	o	o	o	o	o
4.7. Accommodation (e.g. landlords)	o	o	o	o	o

Module 5 is about personal experiences of [X disease] stigma *[branching logic: only shown if people with lived experience of the disease]*

5a. How many times have you experienced the following due to association with [X disease]?

	Never	**Only once**	**A few (2–5) times**	**Many (>5) times**	**Prefer not to say**
5a.1. Negative attitudes towards you	o	o	o	o	o
5a.2. Insulting or inappropriate language (directly towards you or used to describe you, including on social media)	o	o	o	o	o
5a.3. Physical harm or threats of harm (to you or your property)	o	o	o	o	o
5a.4. People avoiding you even when there is no risk of you giving them [X disease]	o	o	o	o	o
5a.5. Disadvantage or exclusion	o	o	o	o	o

[If only once – many times selected above:]

5b. If you are willing to share, who acted in the above way(s) towards you? Select all that apply

Family member(s)/Friend(s)/Neighbour(s)/Co-worker(s)/Classmate(s)/Religious or community leader(s)/Politician(s)/General public/Other/Prefer not to say

Select all that have been true for you at any point since diagnosis:

5c. Having [X disease] made me…

☐ Feel ashamed

☐ Feel less confident

☐ Blame myself for getting [X disease]

☐ Avoid speaking to friends or family

☐ Avoid social gatherings even when recovered

☐ Want to talk to someone who had recovered from [X disease]

☐ Want to help others who may have [X disease]

☐ Willing to share my experience of [X disease] publicly

☐ Prefer not to say

5d. Was anyone close to you (e.g. partner, family) ever treated unkindly because of your [X disease] diagnosis? Yes/No/Unsure/Prefer not to say

5e. Have you ever felt stigmatised (looked down on or treated badly) because of a reason other than [X disease] in the past year? Yes/No/Prefer not to say

Module 6 is about disclosure concerns and social acceptance [branching logic: only shown if no personal history of [X disease]]

6a. If you had [X disease], do you think you would feel comfortable telling the following people about the diagnosis?

		Yes	**Probably**	**Unlikely**	**No**
6.1.	a healthcare worker*	o	o	o	o
6.2.	a new[/recent sexual$^{\$}$] partner	o	o	o	o
6.3.	a close friend or family member	o	o	o	o
6.4.	your workplace/school/college	o	o	o	o

*[*term differed by context; $^{\$}$specified in mpox survey on recommendation of community co-developers. Scoring for regression analyses: mean score across four questions.]*

6b. Please select all that apply below:
I would be willing to accept someone who has recently recovered from [X disease] as...

☐ a new close friend

☐ my doctor

☐ a new neighbour on the same street

☐ a visitor in my region/country

[Question adapted from Bogardus Social Distance Scale[300]. Scoring: one point for each, total = sum score.]

Notes: *term differed by context; $^{\$}$specified in mpox survey on recommendation of community co-developers.

Care-seeking hesitancy

If you had symptoms of [X disease] today, would you choose to delay or avoid seeking medical attention for any reason? Options: Yes / Unsure / No / Prefer not to say

Acceptance of recovered persons (Adapted Bogardus Social Distance Scale)[300]

Please select all that apply below: I would be willing to accept someone who has recently recovered from mpox as…

☐ a new close friend
☐ my doctor
☐ a new neighbour
☐ a visitor in my country/region

Module 7 is about associative stigma:

7a. Do you think any of the following groups are treated (more) negatively due to the [X disease] outbreak? (tick all that apply) [adapted as relevant to outbreak]

☐ People with certain occupations (e.g. healthcare workers, [sex workers, truck drivers])

☐ People from certain countries

☐ People with less money than others in the community

☐ [People of certain races or ethnicities]

☐ [People of certain gender identities (e.g. men, women, non-binary) or trans people]

☐ [People of certain sexual orientations (e.g. gay, lesbian, bisexual)]

☐ Other

Please briefly explain why you selected the options above: [open text]

[Branching logic: Only shown if outbreak responder]

7b. Did you ever feel negatively judged or treated unkindly due to your involvement in responding to the [X disease] outbreak? Yes/No/Prefer not to say

7c. Did the way you were treated during the [X disease] outbreak ever make you consider changing occupations? Yes/No/Prefer not to say

Module 8 is about stigma reduction:

In your opinion:

8. Which of the following would help reduce [X disease] stigma? (tick all that apply)

☐ More public education about [X disease]

☐ More thoughtful public health messages

☐ A recovery certificate for those affected

☐ More psychological support

☐ More laws to stop discrimination

☐ Opportunities to hear the stories of people who have recovered from [X disease]

☐ Awareness campaigns about [X disease] stigma

☐ Other: please specify

Module 9 is about stigma narratives:

9a. Are there any stories you have heard or seen shared about [X disease] or people with [X disease] that you think contribute to stigma? If so, please share them here: [open text]

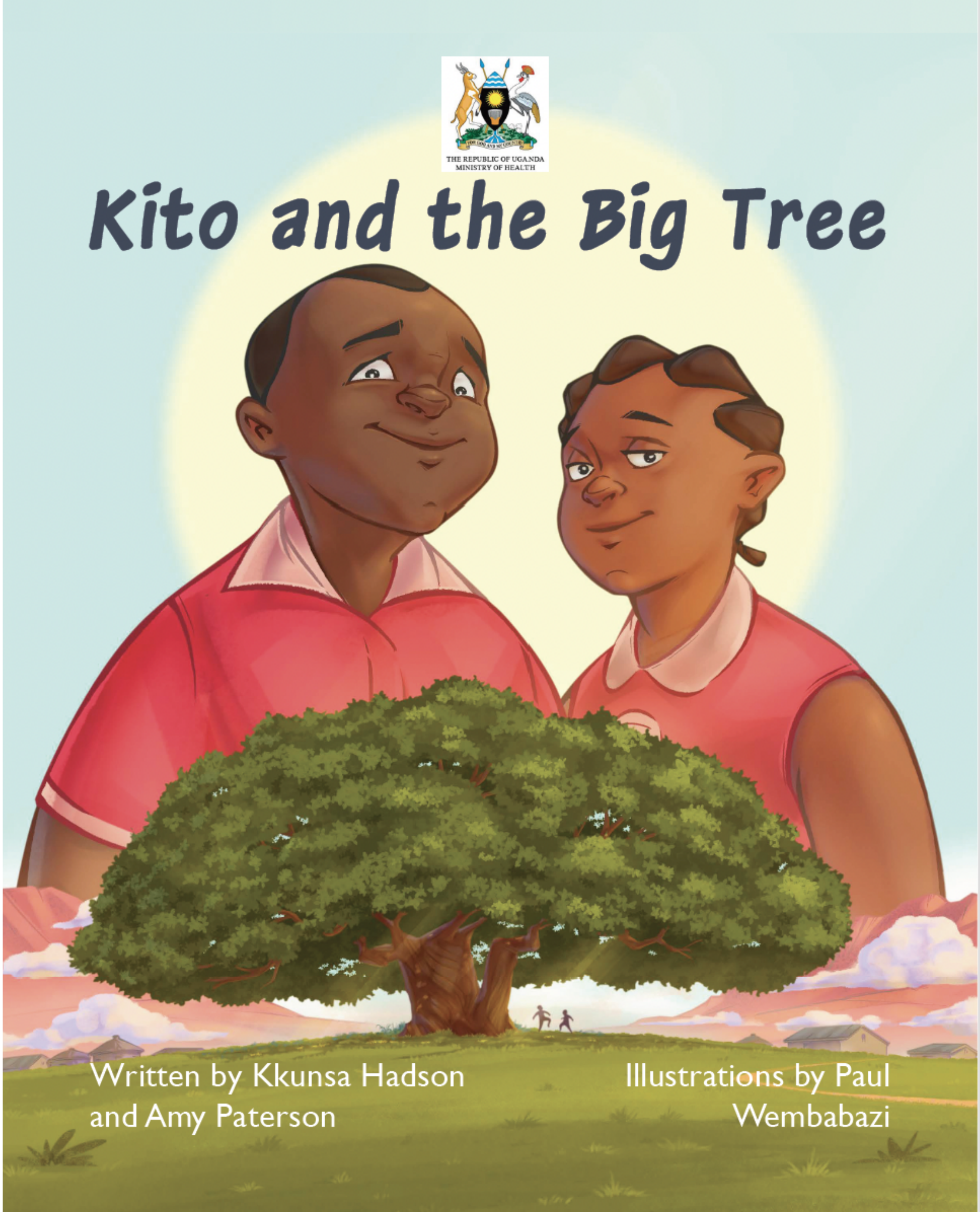
9b. Are there any stories you would like people to share about [X disease] or people with [X disease]? If so, please share them here: [open text]

[RAPID Stigma scales provided in main text]

Thank you for completing this survey. [provide details of support services]

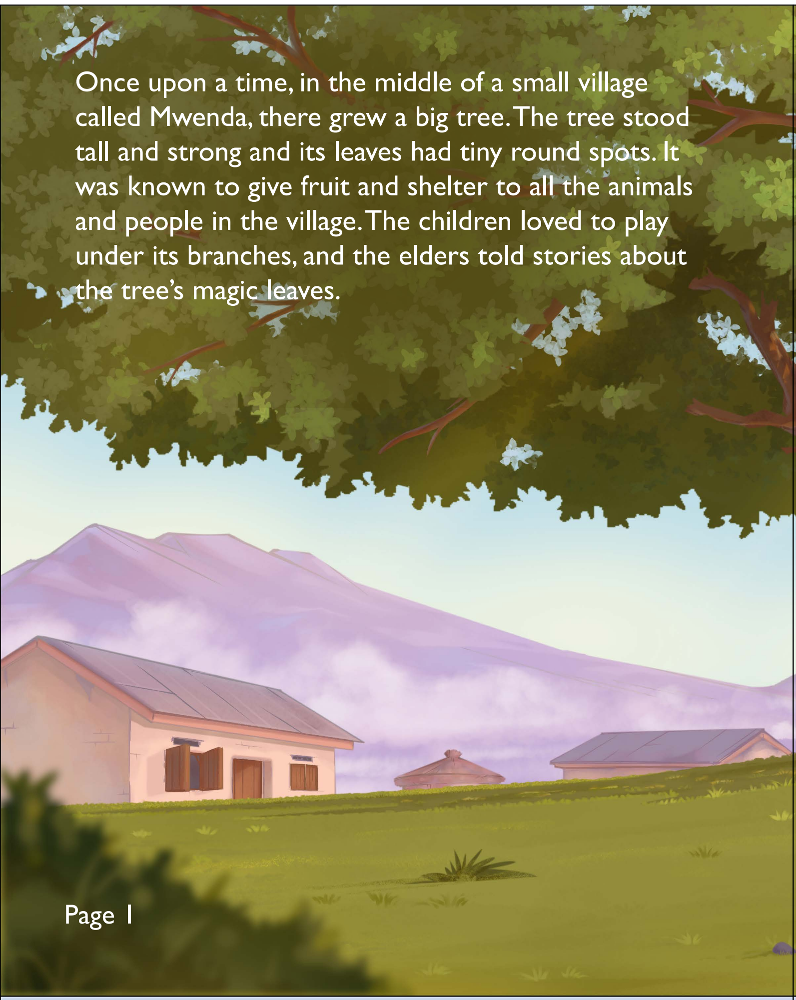
C.21 Anti-stigma children's book

The following appendix contains the full English version of the children's book developed in Uganda based on the Stigma-SCANR findings.

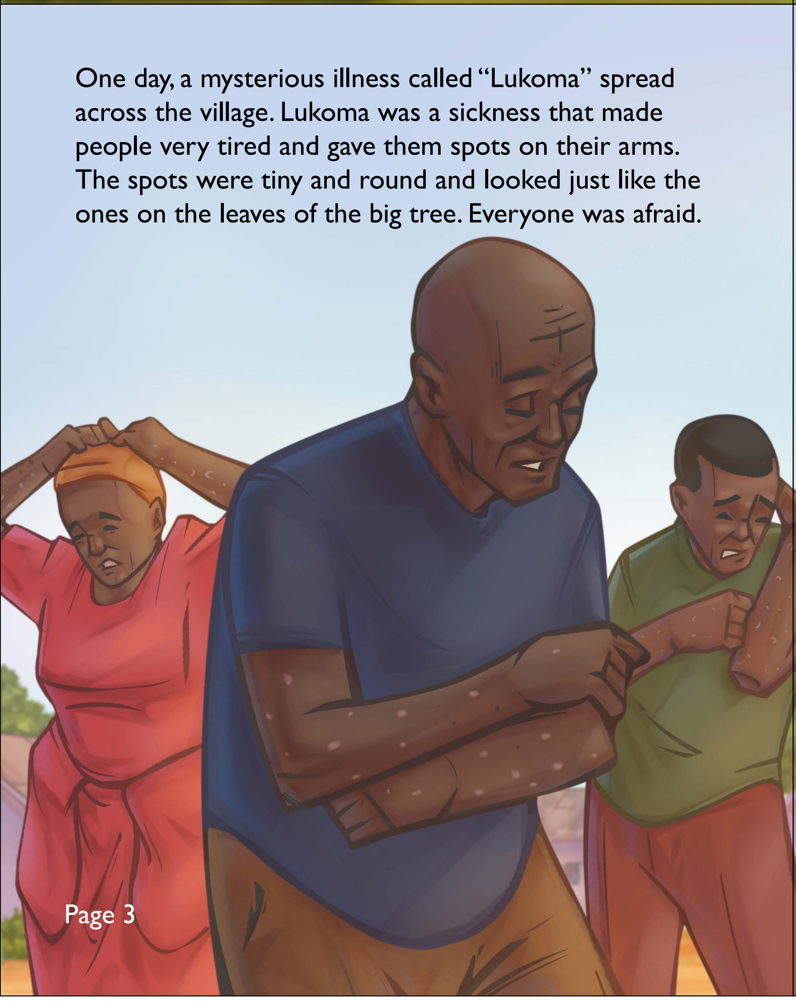


Anti-stigma children's book

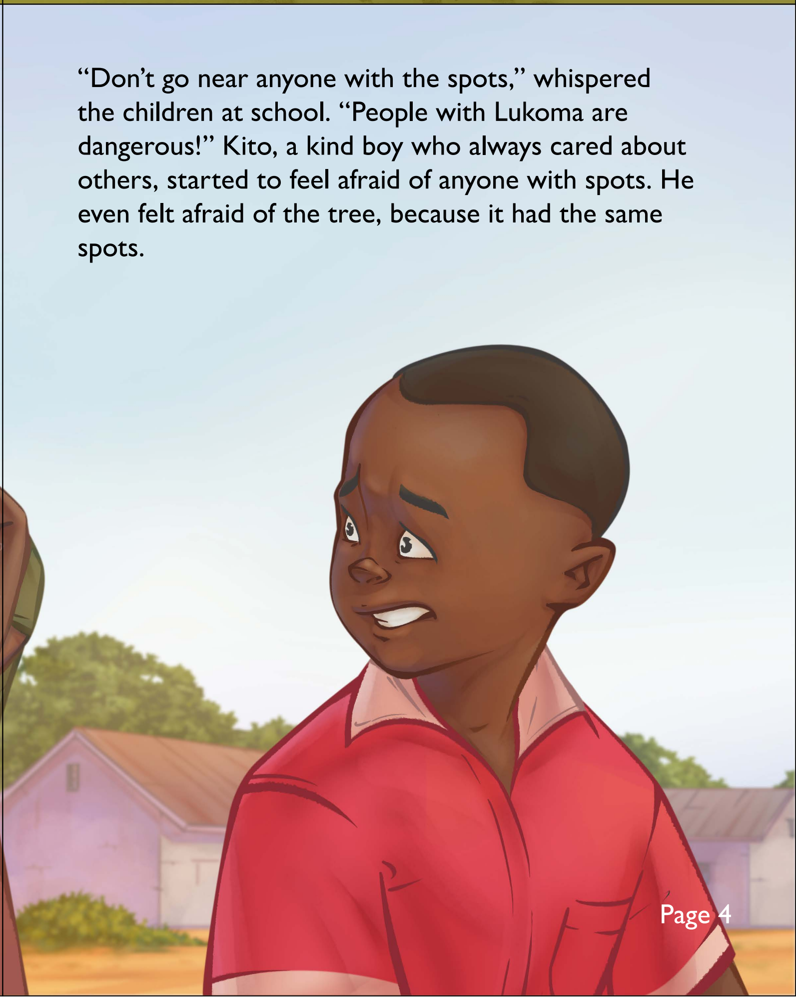
Once upon a time, in the middle of a small village called Mwenda, there grew a big tree. The tree stood tall and strong and its leaves had tiny round spots. It was known to give fruit and shelter to all the animals and people in the village. The children loved to play under its branches, and the elders told stories about the tree's magic leaves.



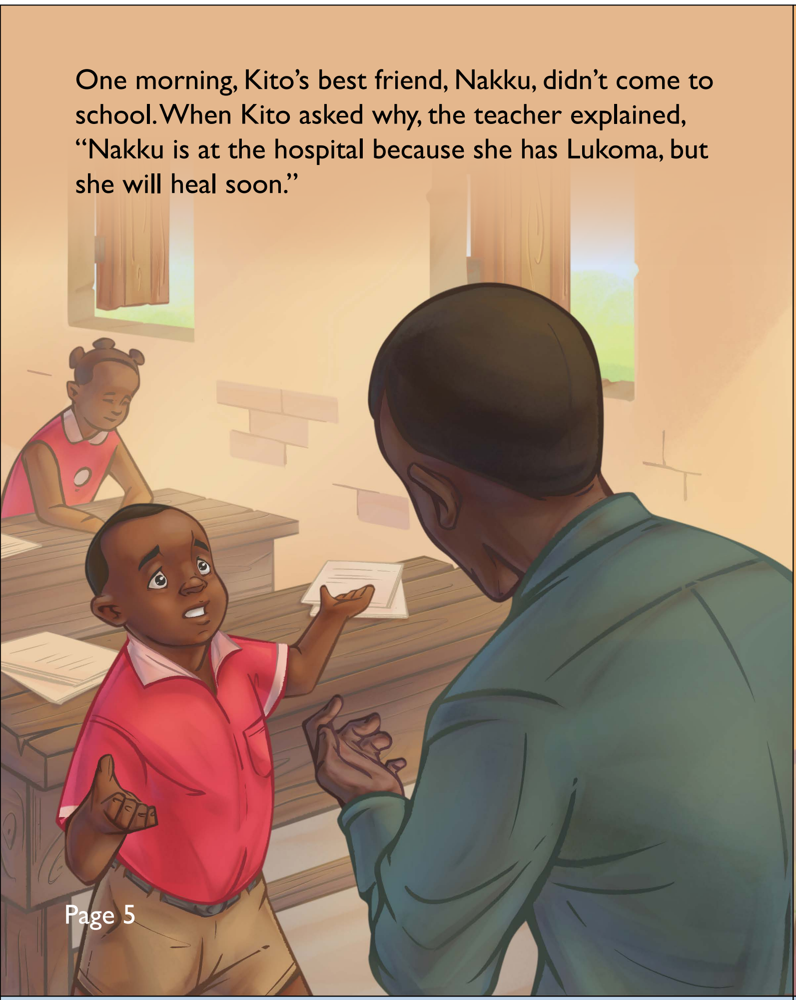
One day, a mysterious illness called "Lukoma" spread across the village. Lukoma was a sickness that made people very tired and gave them spots on their arms. The spots were tiny and round and looked just like the ones on the leaves of the big tree. Everyone was afraid.



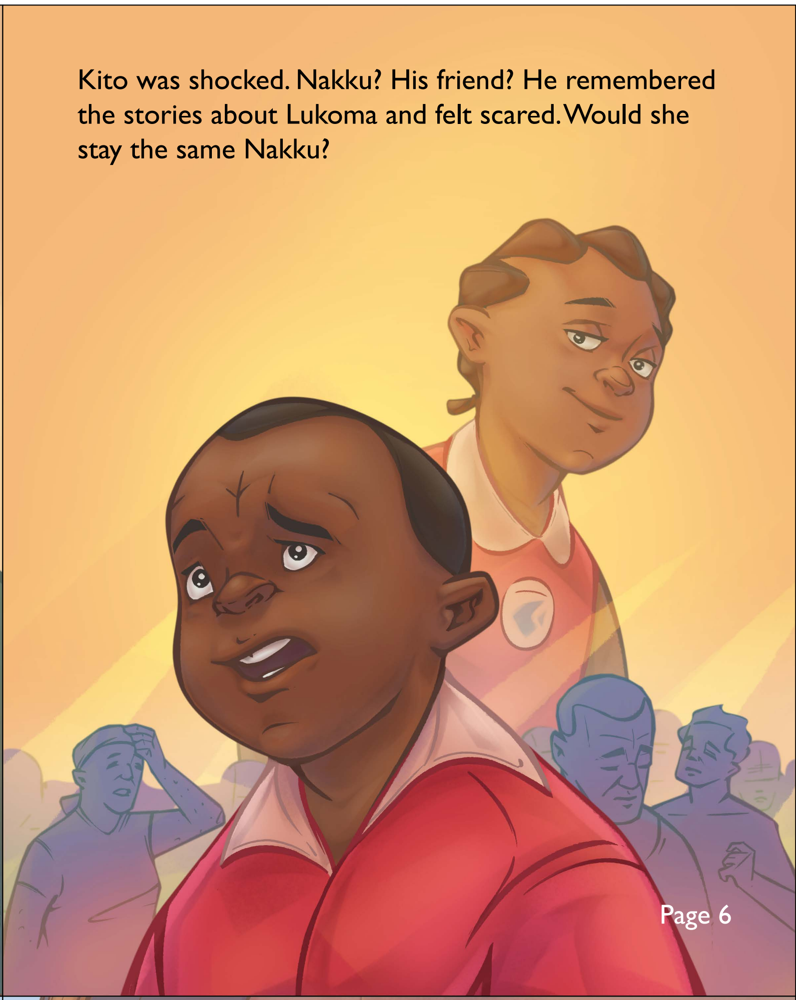
"Don't go near anyone with the spots," whispered the children at school. "People with Lukoma are dangerous!" Kito, a kind boy who always cared about others, started to feel afraid of anyone with spots. He even felt afraid of the tree, because it had the same spots.



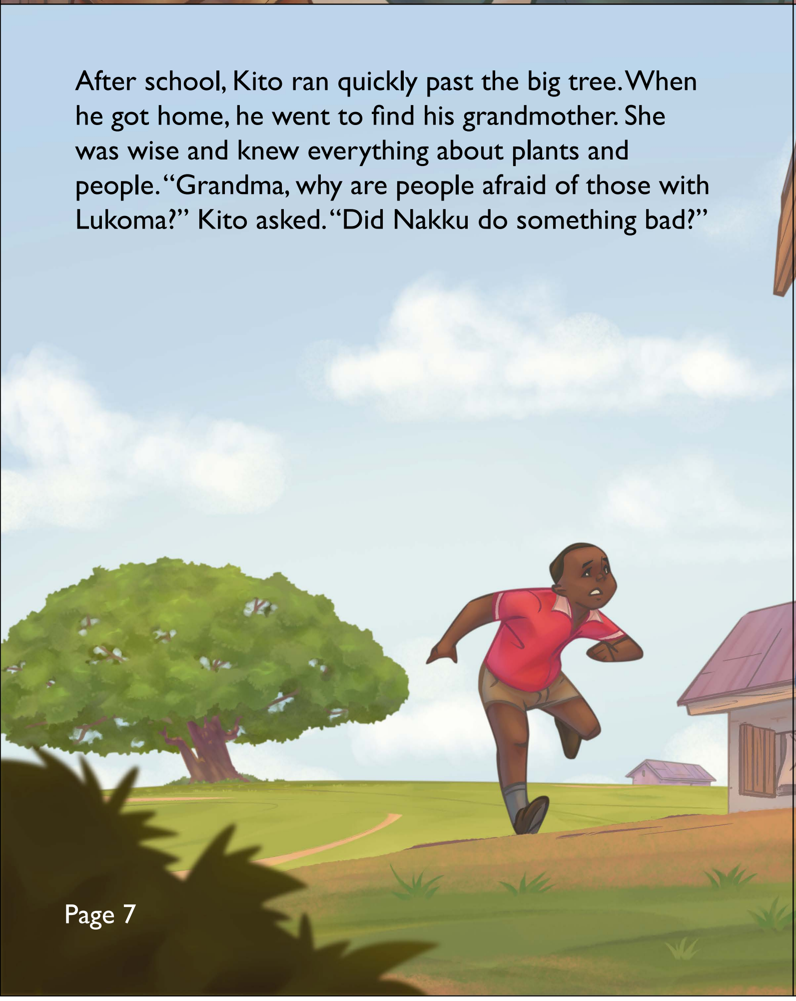
One morning, Kito's best friend, Nakku, didn't come to school. When Kito asked why, the teacher explained, "Nakku is at the hospital because she has Lukoma, but she will heal soon."



Kito was shocked. Nakku? His friend? He remembered the stories about Lukoma and felt scared. Would she stay the same Nakku?



After school, Kito ran quickly past the big tree. When he got home, he went to find his grandmother. She was wise and knew everything about plants and people. "Grandma, why are people afraid of those with Lukoma?" Kito asked. "Did Nakku do something bad?"

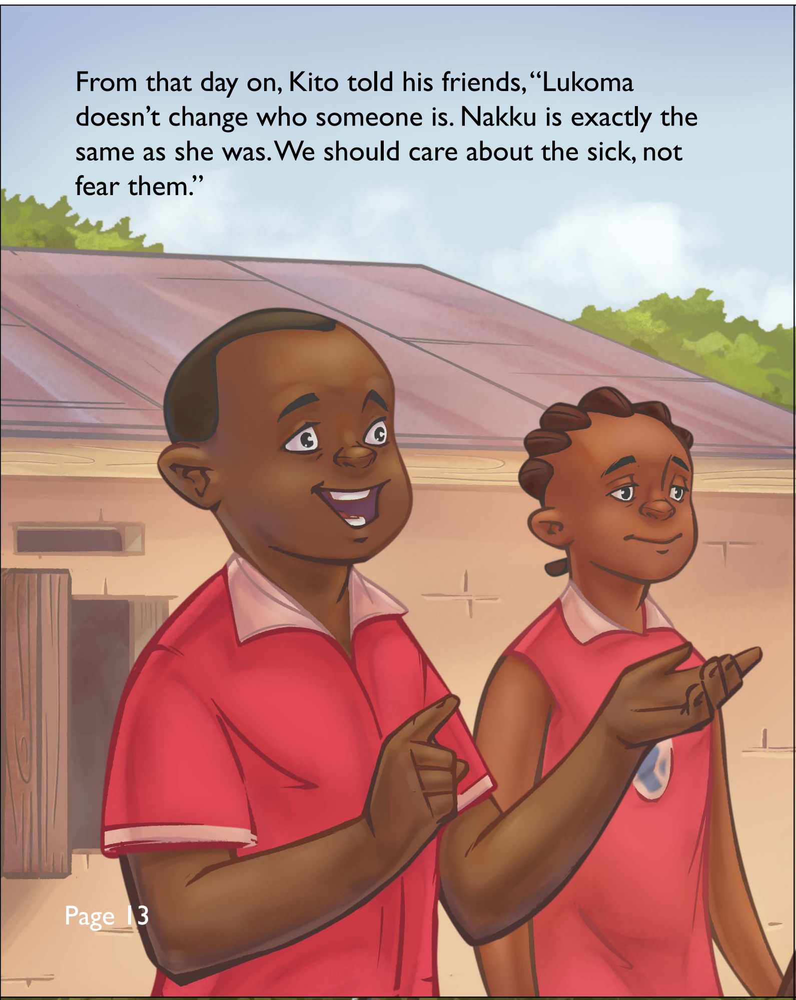


Grandma smiled kindly. “Kito, Lukoma is just a sickness, like a cold or a fever. People get sick, but they also get better.

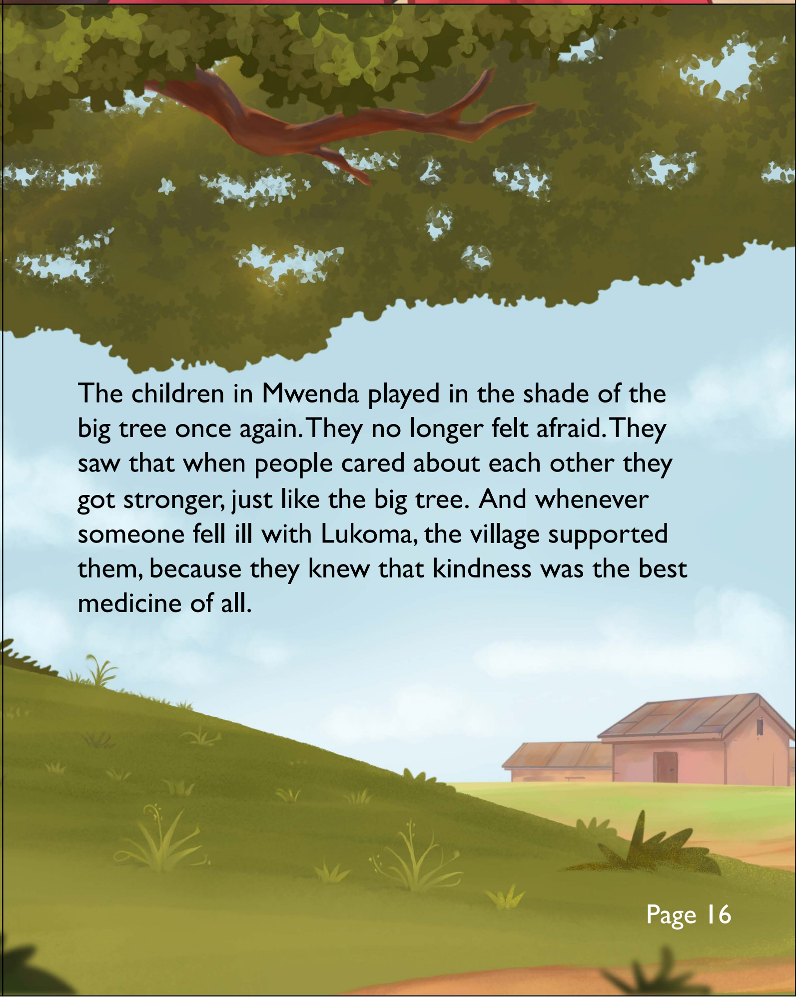
Just because Nakku has Lukoma doesn’t mean she’s any different. She’s still your friend, and she needs people to be there for her, not be afraid of her.”

Kito thought about Grandma’s words and how lonely Nakku must feel. He gathered some of Nakku’s favourite fruits from the big tree and took them to the hospital. He added a note that said “I’m here for you.” Under it he drew a picture of them playing together.

A few weeks later, Nakku returned to school. Her spots had faded. She smiled at Kito. “Thank you for not being afraid of me,” she said. “Knowing you were still my friend made me feel stronger.”



From that day on, Kito told his friends, “Lukoma doesn’t change who someone is. Nakku is exactly the same as she was. We should care about the sick, not fear them.”



The children in Mwenda played in the shade of the big tree once again. They no longer felt afraid. They saw that when people cared about each other they got stronger, just like the big tree. And whenever someone fell ill with Lukoma, the village supported them, because they knew that kindness was the best medicine of all.

BE KIND AND STAY SAFE

- Being sick does not mean the person is bad. They are still the same friend/classmate
- Illness is not any person's fault. Sickness can happen to anyone
- You can support a sick person without touching them
- Tell an adult or call for help if you see that someone is unwell so they can be supported
- Avoid nicknaming or gossiping about someone just because they were sick
- Always wash your hands to protect yourself from infections
- Listen to teachers, parents, and health workers and follow their advice
- Give someone time to rest and heal. Be kind and respectful
- Celebrate when friends return to school after recovery
- Remember: kindness spreads faster than any sickness!

walimu
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This work was inspired by a research project looking at Ebola related stigma.

We want to thank everyone who took part in the research project, with special thanks to the Ebola survivors for sharing their stories.

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D

Appendices for anti-stigma guideline development

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D.1 Search strategy for systematic review of stigma reduction interventions

Search terms for the key components ‘stigma’ or ‘social acceptance’ and ‘infectious disease outbreaks’ were combined using Boolean operators to search keyword fields and indexed subject headings. To determine the search terms for infectious disease outbreaks the following lists were reviewed: the WHO list of priority diseases,[83] the UK government’s list of High Consequence Infectious Diseases,[301] the WHO outbreak news reports,[302] and the CDC’s list of international outbreaks.[303] Any disease that occurred on more than one list was named in the search terms.

Stigma or social acceptance-related terms included: *(stigma* OR prejudic* OR (discriminat* NOT ((discriminat* ADJ power) OR (discriminat* ADJ abilit*))) OR shame OR embarrass* OR humiliat* OR disapprov* OR (social* ADJ exclu*) OR (community ADJ exclu*) OR (social* ADJ reject*) OR (community ADJ reject*) OR marginali* OR ostraci* OR (social* ADJ accept*) OR (community ADJ accept*) OR (self ADJ accept*) OR (social* ADJ inclusi*) OR (community ADJ inclusi*) OR (social* ADJ approv*) OR (community ADJ approv*) OR reintegrat* OR (self ADJ worth) OR (self ADJ esteem) OR (self ADJ confidence)) along with related indexed terms (database dependent)*

Outbreak-related terms included: *((infectious ADJ disease*) OR outbreak* OR epidemic* OR pandemic* OR (emerging ADJ disease*) OR (emerging ADJ infect*) OR (priority ADJ pathogen*) OR COVID-19 OR Coronavirus OR SARS* OR (severe ADJ acute ADJ respiratory ADJ syndrome) OR (Middle ADJ East ADJ respiratory ADJ syndrome) OR MERS-CoV OR (avian ADJ influenza*) OR (bird ADJ flu) OR H5N1 OR H7N9 OR H7N7 OR H5N6 OR Zika OR Ebola OR ebolavirus OR (Sudan ADJ virus) OR (haemorrhagic ADJ fever*) OR (hemorrhagic ADJ fever*) OR Marburg OR CCHF OR Nipah OR henipavir* OR (Lassa ADJ fever) OR Dengue OR (Rift ADJ Valley ADJ fever) OR mpox OR monkeypox OR measles OR plague OR (Yersinia ADJ pestis) OR oropouche) along with related indexed terms (database dependent)*

D.2 Systematic review eligibility criteria

Eligibility criteria for systematic review of stigma reduction interventions

Criteria	Inclusion	Exclusion
Population	Studies that include participants of any age, gender, or geographic location who are affected by, endorse, enact, or are positioned to influence stigma associated with an infectious disease outbreak. These may be individuals with or without personal experience of the disease.	Studies focused on non-outbreak disease contexts. Studies focused on marginalised groups being stigmatised during the time period of an outbreak but not due to association with the disease.
Intervention	Studies that describe the implementation of at least one intervention (including adaptations to policies and procedures) intended to reduce stigma associated with an outbreak-prone infectious disease.	Studies that describe general stigma reduction measures not applied to the context of infectious disease outbreaks.
Comparison	Studies that include a description of the evaluation of the interventions in comparison to routine practice, alternative interventions, or no intervention.	Studies without clear evaluation of effectiveness of interventions.
Outcome	Studies that report the effectiveness of interventions in reducing any form of outbreak-related stigma or improving social acceptance.	Studies that do not provide relevant data on intervention impact on stigma.
Study design	Peer-reviewed studies with comparative/evaluative design including: - Randomised controlled trials - Quasi-experimental studies - Observational studies with comparative design - Mixed-methods studies - Qualitative studies	Studies without a comparative or evaluative component; studies relying solely on conceptual discussions or theoretical models; protocols, guidelines, book sections, case reports, opinion pieces (editorials, viewpoints, commentaries); conference abstracts; preprints and other non-peer-reviewed literature.

D.3 WHO-INTEGRATE criteria used for evidence appraisal

WHO-INTEGRATE criteria, sub-criteria, and sources of evidence used in evidence to recommendations process

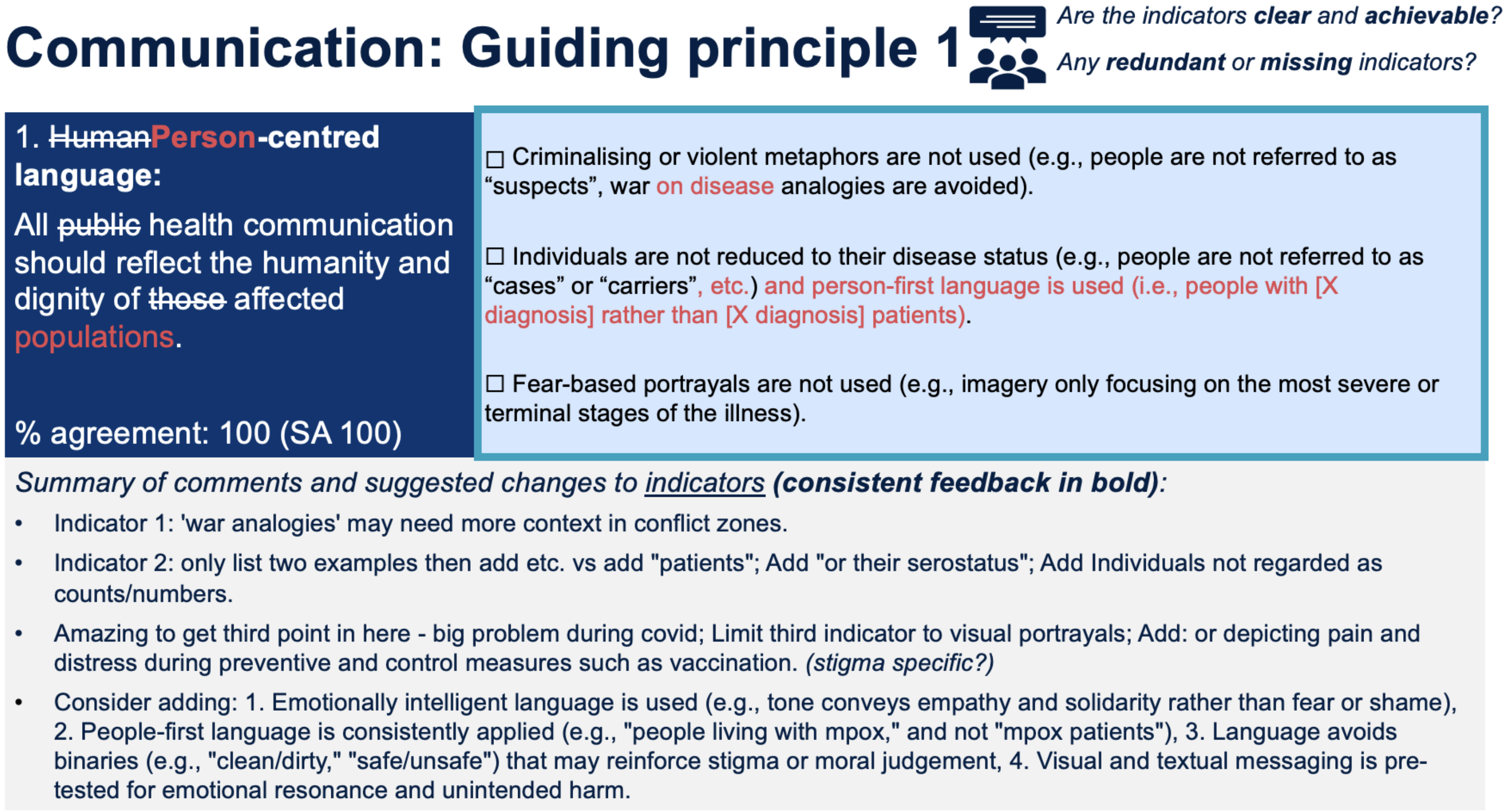
WHO-INTEGRATE Criteria	Sub-criteria used	Sources of evidence
Balance of health benefits and harms	• Efficacy or effectiveness on health of individuals • Effectiveness or impact on health of population • Safety-risk-profile of intervention • Broader positive or negative health-related impacts	Systematic review findings (quantitative and qualitative), supplemented by indirect evidence from non-outbreak contexts.
Health equity, equality, and non-discrimination	• Distribution of benefits and harms • Accessibility of intervention • Impact on health equity	Systematic review findings, survey data, supplemented by indirect evidence from non-outbreak contexts, and stakeholder interviews.
Societal implications	• Social impact	Systematic review findings, survey data, supplemented by indirect evidence from non-outbreak contexts, and stakeholder interviews.
Human rights and socio-cultural acceptability	• Accordance with universal human rights standards • Socio-cultural acceptability to patients/beneficiaries and implementers • Socio-cultural acceptability to the public and stakeholders • Impact on autonomy	Stakeholder interviews and survey data across three outbreak contexts, indirect systematic reviews and additional non-interventional literature.
Feasibility and health system considerations	• Leadership and governance • Interaction with and impact on health system • Need for and impact on workforce and human resources • Need for and impact on infrastructure	Feasibility comments/themes from stakeholder interviews, community surveys, and qualitative studies; indirect inference from reviews.
Financial and economic considerations	• Financial impact • Ratio of costs and benefits	Limited direct cost data; inference from feasibility discussions in stakeholder interviews and cost-effectiveness data from reviews when available.

Continued on next page

Table D.2 – continued from previous page

WHO-INTEGRATE Criteria	Sub-criteria used	Sources of evidence
Meta-criterion	• Quality of evidence	Based on initial systematic review assessments, then adjusted according to appraisal of full body of supporting evidence using GRADE-CERQual criteria (methodological limitations, coherence, adequacy, relevance).

D.4 Illustrative meeting slide used in consensus process



Communication: Guiding principle 1

*Are the indicators **clear** and **achievable**?*

*Any **redundant** or **missing** indicators?*

1. ~~Human~~Person-centred language:

All ~~public~~ health communication should reflect the humanity and dignity of ~~those~~ affected populations.

% agreement: 100 (SA 100)

☐ Criminalising or violent metaphors are not used (e.g., people are not referred to as "suspects", war on disease analogies are avoided).

☐ Individuals are not reduced to their disease status (e.g., people are not referred to as "cases" or "carriers", etc.) and person-first language is used (i.e., people with [X diagnosis] rather than [X diagnosis] patients).

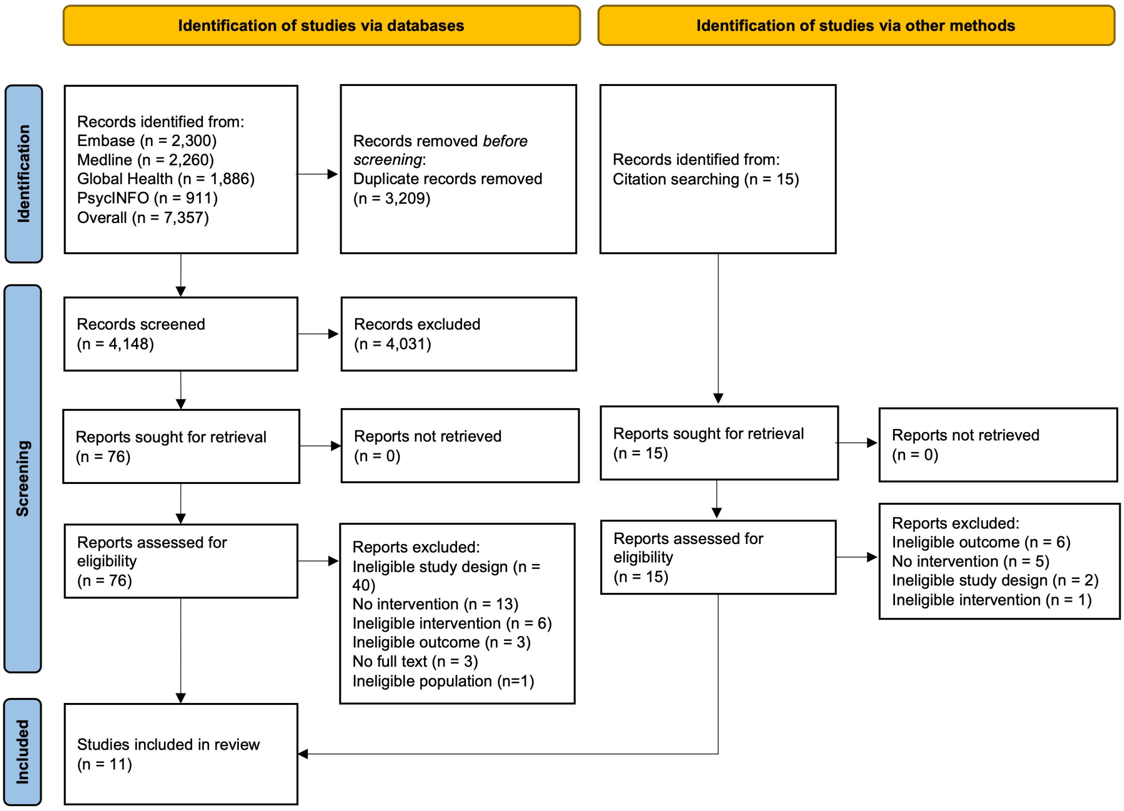
☐ Fear-based portrayals are not used (e.g., imagery only focusing on the most severe or terminal stages of the illness).

*Summary of comments and suggested changes to indicators **(consistent feedback in bold)**:*

- Indicator 1: 'war analogies' may need more context in conflict zones.
- Indicator 2: only list two examples then add etc. vs add "patients"; Add "or their serostatus"; Add Individuals not regarded as counts/numbers.
- Amazing to get third point in here - big problem during covid; Limit third indicator to visual portrayals; Add: or depicting pain and distress during preventive and control measures such as vaccination. *(stigma specific?)*
- Consider adding: 1. Emotionally intelligent language is used (e.g., tone conveys empathy and solidarity rather than fear or shame), 2. People-first language is consistently applied (e.g., "people living with mpox," and not "mpox patients"), 3. Language avoids binaries (e.g., "clean/dirty," "safe/unsafe") that may reinforce stigma or moral judgement, 4. Visual and textual messaging is pre-tested for emotional resonance and unintended harm.

Example of expert meeting slides

D.5 Systematic review PRISMA diagram



PRISMA diagram for outbreak-specific stigma reduction systematic review, adapted from Page et al.[114] under CC BY 4.0.

D.6 Characteristics of studies included in systematic review

Details of studies included in systematic review

1st author, year	Country, disease	Population	Sample size	Intervention	Stigma measure; any validation	Outcome; risk of bias
Randomised controlled trials						
Islam, 2021[245]	India, COVID-19	Adult residents	1081 (intervention); 1057 (control)	Phone-based delivery of accurate COVID-19 information and anti-stigma messaging.	Two composite stigma measures; no	Reduced stigma, some concerns for bias†
Lu, 2021[250]	China, COVID-19	Wuhan students returning to non-Hubei provinces	31 (intervention); 32 (control)	Brief, online 'social support' reading and writing psychological exercise	Perceived Personal Discrimination Scale; yes	Reduced stigma; some concerns for bias†
Smith, 2012[248]	US, Disease X	Undergraduate students	333 (distributed across 16 experimental conditions)	Exposure to different messaging in a hypothetical infectious disease alert	Stigma beliefs scale and support for restrictive interventions; yes	Increased stigma with high-peril messaging, some concerns for bias†
Techapoonpon, 2023[251]	Thailand, COVID-19	Recovered persons prior to discharge	71 (intervention); 71 (control)	Brief, self-directed online programme on COVID-19 stigma and emotional first aid techniques	Adapted version of COVID-19-related stigma questionnaire 29; yes	Reduced stigma, some concerns for bias†
Tidwell, 2024[304]	Kenya, COVID-19	Residents of informal settlements	515 (intervention 1); 516 (intervention 2); 494 (control)	Additions to anti-stigma text messages emphasising 1) reciprocity or 2) importance of community support	Survey of knowledge, attitudes and behavioural intentions; no	No change, some concerns for bias†

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Table D.3 – continued from previous page

1st author, year	Country, disease	Population	Sample size	Intervention	Stigma measure; any validation	Outcome; risk of bias
Valeri, 2021[244]	US, COVID-19	Adult residents	250 (control); 243 (intervention 1); 249 (intervention 2); 246 (intervention 3)	1) disease information sheet only, 2) + video encouraging online social support, or 3) + video of affected person describing experiences	Adapted HIV stigma scale; no	Reduced stigma (Intervention 2 & 3), high risk of bias†
Wang, 2024[305]	China, COVID-19	Male adults	70 (within-sample, before and after comparison)	24IU intranasal oxytocin (based on evidence of promoting pro-social behaviour and empathy)	Stigma judgment paradigm; yes	No change, low risk of bias†
Qualitative studies						
Biesty, 2024[217]	UK, mpox	Outbreak responders and GBMSM	11 (key informant interviews); 15 (workshops)	Community-led public health messages and campaigns	Qualitative interviews/focus groups; N/A	Mixed results, largely reduced stigma; mostly methodologically sound*
Collier, 2023[227]	Sierra Leone, Ebola disease	Affected community members/leaders	134 total participants	Involving survivors, local leaders, teachers, and community health workers in disease education and survivor reintegration	Qualitative interviews/focus groups; N/A	Reduced stigma; mostly methodologically sound*
Crea, 2022[306]	Sierra Leone, Ebola disease	Affected community members/leaders	228 total participants	Community protection bylaws and stigma-focused education efforts by community leaders and outbreak responders	Qualitative interviews/focus groups; N/A	Mixed results; mostly methodologically sound*
Siu, 2008[307]	Hong Kong, SARS	Recovered persons	170 (observation only); 30 (in-depth interview)	Follow up clinics for SARS survivors with separate entrances and elevators	Qualitative interviews/observation; N/A	Increased stigma, mostly methodologically sound*

*Assessed with CASP qualitative studies checklist. † Assessed with Cochrane revised risk of bias for RCTs tool (RoB 2). COVID-19: Coronavirus Disease 2019; IU: international units; SARS: severe acute respiratory syndrome; UK: United Kingdom; US: United States

D.7 Characteristics of supporting literature: non-outbreak reviews

Details of reviews of stigma reduction interventions in non-outbreak infectious disease contexts

First author, year	Infectious diseases	No. of relevant studies; study designs (focus)	Intervention(s)	Findings; confidence in findings*
Anindhita, 2024[308]	HIV, leprosy, TB	30 studies; quantitative, qualitative, mixed methods (effectiveness and mechanisms in low-and middle-income countries)	Community-based psychosocial support delivered by trained peer and lay providers	Reduction in community and self stigma, interventions co-designed and implemented with affected communities more likely to be accepted and sustained. Low-cost tools such as peer counselling, storytelling, and community videos were effective if peer and lay providers given adequate training and support; moderate
Chang, 2014[309]	TB	83 studies; quantitative, qualitative, mixed methods (descriptive, focused on how to mitigate exacerbating factors)	Health facility practices and public health measures	Healthcare worker fear of infection and restrictive public health practices such as prohibition of full burial rites exacerbate stigma; low
Driedger, 2018[310]	HIV, TB, hepatitis B/C	11 systematic reviews; qualitative (acceptability, accessibility, and prioritisation for migrants and displaced persons in the European Economic Area)	Health facility practices and public health measures	Engagement with interventions is strongly influenced by cultural sensitivity, trust in healthcare providers, and perceived disease risk; medical interpreters resulted in reluctance to report symptoms due to confidentiality concerns; moderate
Feyissa, 2015[311]	HIV	9 studies; quantitative (effectiveness)	Home based HIV counselling and testing	Meta-analysis indicated that the risk of observing or experiencing any stigmatising behaviour in the community was significantly lower among home-based cohort; moderate

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Table D.4 – continued from previous page

First author, year	Infectious diseases	No. of relevant studies; study designs (focus)	Intervention(s)	Findings; confidence in findings*
Gronholm, 2021[225]	HIV, leprosy, TB	6 systematic reviews; mixed evidence synthesis (effectiveness, prioritisation)	Language guidance, communication training, mass media, art-based mediums, mental health programmes, information sharing to community leaders and peers, policing and criminalising, universal public health measures	Mixed results e.g. policing reported to increase stigma, universal public health measures reported to decrease stigma; high
Hartog, 2020[162]	HIV, filariasis, leprosy, TB	61 studies; quantitative, qualitative (effectiveness for affected children and adolescents)	Community education, individual empowerment, social contact	Ten distinct child-focused strategies (mostly printed material and films) were evaluated positively; low
Hofstraat, 2016[253]	Neglected tropical diseases	52 studies; quantitative, qualitative, mixed methods (effectiveness)	Stigma targeted health education, integrated psychosocial support, community contact	To be effective, health education needs to address specific cultural and religious beliefs, and the specific questions and fears that people have in a given community, and be combined with other interventions, focusing on psychosocial impact during disease management considered effective; low
Kemp, 2019[312]	HIV, filariasis, leprosy, TB	35 studies; quantitative, qualitative (acceptability, adoption, appropriateness, feasibility, fidelity, cost, penetration, and/or sustainability)	School-based peer education programme, comic book aimed to reduce stigma for school children, information sharing/education	Interventions need to be culturally relevant and address structural factors, with contact-based strategies and rights-based peer counselling showing promise; moderate
Layland, 2020[313]	HIV	40 studies; quantitative (integration of stigma reduction into health interventions for sexual and gender minorities)	Intersectional interventions that target both sexual and gender minority status and health status	Frequent lack of intersectional framework, sources of stigma beyond sexual and gender minority identities rarely addressed; low

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Table D.4 – continued from previous page

First author, year	Infectious diseases	No. of relevant studies; study designs (focus)	Intervention(s)	Findings; confidence in findings*
Majeed, 2024[314]	HIV	192 studies; quantitative (effectiveness)	Educational interventions, social contact, increased access to services, counselling/mentoring, social activism	Mostly positive reduction in stigma, but no association between nature of intervention and change in stigma outcomes; low
Nyblade, 2019[155]	HIV	37 studies; quantitative, qualitative, mixed methods (effectiveness in healthcare settings)	Workshops for healthcare workers (lecture, discussion, role-play) including those led by people living with HIV (with testimony), training hospital champions of stigma reduction, provision of universal precaution materials, integration of HIV care into primary services	Mixed effect on provider-related stigma, many interventions targeted knowledge of disease, management of condition or knowledge of stigma which may not directly translate to reduced stigma; moderate
Rao, 2019[315]	HIV, leprosy	24 studies; quantitative (effectiveness)	Education, contact, coping skills acquisition, social support, drama, problem solving	Mixed results in stigma reduction (typically in the small-to-moderate range), fewer than half the studies reported measures of practical significance (i.e. effect size); low
Sengupta, 2011[316]	HIV	19 studies; quantitative (effectiveness)	Information sharing, skill-building, counselling and testimony from people living with HIV	14 of 19 studies reported stigma reduction but methodological flaws in most studies noted; moderate
Stangl, 2013[317]	HIV	48 studies; quantitative, qualitative (effectiveness, acceptability, prioritisation)	Information sharing, skills building, contact, counselling and support, structural changes, biomedical changes (e.g. introduction of ART)	Mixed results (mostly reduction in stigma); moderate
Stangl, 2023[318]	HIV	23 studies; quantitative (effectiveness, intersectional benefits)	Multi-strategy (information, skills building, counselling support, contact, structural, biomedical, expressive writing)	Mixed results (half showed reduction in stigma); moderate

*Confidence in findings assessed using AMSTAR 2 checklist, adapted to make Criterion 7 (listing all excluded studies) a non-critical domain, due to feasibility constraints for large reviews (in accordance with AMSTAR 2 guidance on adapting domain assessment depending on review context).[238]
ART: antiretroviral therapy; HIV: human immunodeficiency virus; TB: tuberculosis.

D.8 Characteristics of supporting literature: non-interventional studies

Details of supporting literature: non-interventional studies

First author, year	Country/Regio Disease	Outbreak phase	Population	Sample size	Findings; risk of bias*
Qualitative studies					
Fargnoli, 2021[319]	Switzerland; COVID-19	Response	Members of public, public health decision makers	11 in focus groups, 14 interviews	Recovery certificates mostly not accepted, considered potentially harmful; mostly methodologically sound*
Lamb, 2018[320]	UK (with deployment to West Africa); Ebola disease	Response	UK Armed Forces medical personnel	14 interviews	Pre-deployment training generated competence, cohesiveness and resilience; mostly methodologically sound*
Musoke, 2025[321]	Uganda; Ebola disease	Response	Community members, health workers, community leadership	25 in focus groups, 32 interviews	Delayed consultation, poor communication, limited human resources support, coordination challenges regarded as barriers to community engagement; mostly methodologically sound*
Nyarko, 2015[322]	Ghana; Ebola disease	Preparedness	Health professionals	15 roundtable participants	Co-creating anti-stigma educational messaging with community groups recommended by healthcare workers; mostly methodologically sound*
Parveen, 2016[323]	Bangladesh; Nipah virus disease	Preparedness/	Community members, religious leaders, caregivers	10 informal discussions, 11 interviews, 4 in focus groups, community meetings	Suggests using culturally tailored two-way communication, e.g. image-based dialogue session more acceptable; mostly methodologically sound*

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Table D.5 – continued from previous page

First author, year	Country/Regio Disease	Outbreak phase	Population	Sample size	Findings; risk of bias*
Person, 2004[29]	US; SARS	Response	Asian American community leaders and other stakeholders	70 in group discussions	Suggestions to develop tailored prevention messaging, Asian-language materials, partnerships with community organisations, ensure ongoing active mitigation; mostly methodologically sound*
Zalwango, 2024[195]	Uganda; Ebola disease	Response	Survivors, household members, district officials, health workers	30 interviews	Community and self isolation, rejection, loss of work, exclusion from community and education described; worsened by health worker follow up; mostly methodologically sound*
Observational studies					
Ford, 2021[324]	US; COVID-19	Preparedness/ Response	Environmental scan of systems to monitor racism, social stigma and COVID inequities	10 surveillance systems	Existing systems do not adequately capture real-time data; N/A
Kwon, 2022[325]	US; COVID-19	Response	Adults	8386 survey respondents	Mixed results; mask wearers stigmatised before mandates, reversal after mandates introduced; serious concerns§

*Assessed with CASP qualitative studies checklist or Risk Of Bias In Non-randomized Studies of Intervention Version 2 tool (ROBINS-I V2) as applicable. Abbreviations: CDC: Centers for Disease Control and Prevention; COVID-19: Coronavirus Disease 2019; Ebola disease: Ebola virus disease; FGD: focus group discussion; HCW: healthcare worker; HR: human resources; N/A: not applicable; SARS: severe acute respiratory syndrome; US: United States of America

D.9 Anti-stigma guiding principle rationales

Guiding principles with rationales and supporting rights and ethical principles

Guiding principles	Brief rationale	Supporting rights and principles
Communication and knowledge exchange		
1. All health communication should reflect the humanity and dignity of affected populations.	This principle reflects an understanding that language can shape perceptions and behaviours, contributing to empathy or stigma.	Universal Declaration of Human Rights (UDHR) Article 1 (right to dignity)[326]; World Medical Association Declaration of Geneva (medical duty to uphold patient dignity).[327]
2. Messaging should not imply that specific groups are responsible for the outbreak.	Outbreaks result from a complex combination of factors, not the actions of any specific group. Messaging that implies blame or portrays disease as innately linked to a particular population can exacerbate stereotypes.	International Covenant on Civil and Political Rights (ICCPR) Article 20 (prohibition of incitement)[328]; UDHR Article 12 (protection against attacks on reputation)[326]; WHO best practices for naming diseases.[329]
3. Outbreak communication mechanisms should be designed for two-way engagement with communities.	Effective communication that involves discussion rather than unidirectional instruction can help ensure stigmatising misinformation is addressed and messaging is contextually-sensitive.	ICCPR Article 25 (right to participation)[328]; WHO definition of risk communication[330]; WHO guidance on ethical issues in outbreaks (inclusive engagement, autonomy).[331]
Policy and governance		
4. Affected communities should be meaningfully engaged in decisions that impact them.	Affected communities should have a voice in the actions that influence their wellbeing. This involvement also helps to design more effective and stigma-sensitive interventions.	Universal Declaration on Bioethics and Human Rights Article 5[332]; ICCPR Article 25 (participation)[328]; WHO Framework on Integrated People-Centred Health Services.[333]

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Table D.6 – continued from previous page

Guiding principles	Brief rationale	Supporting rights and principles
5. Outbreak response institutions should model the inclusive and transparent behaviours they promote.	Institutional trustworthiness is a prerequisite for building lasting community trust. Stigma needs to be addressed within institutions before it can be effectively addressed externally.	ICCPR Article 26 (right to non-discrimination)[328]; WHO guidance (accountability in health systems).[331]
6. The effectiveness and adverse effects of outbreak control measures and stigma reduction interventions should be assessed and transparently reported.	Evaluating and documenting stigma-related outcomes enables shared learning and strengthens accountability in outbreak response.	International Covenant on Economic, Social and Cultural Rights Article 15 (benefit from scientific progress)[334]; UDHR Article 12 (privacy, reputation)[326]; WHO guidance (social harms and reporting).[331]
Service design and delivery		
7. Outbreak services should be designed to minimise dehumanisation and alienation.	Service environments that undermine privacy, use othering terminology, or treat individuals disrespectfully can reinforce stigma and deepen social exclusion.	WHO guidance (means to communicate, respect for belongings)[331]; UDHR Articles 1 and 21 (dignity, equal access to public services).[326]
8. Outbreak measures should be evidence-based and no more restrictive than necessary to minimise social disruption.	Introducing outbreak measures that are excessively restrictive and/or not rooted in evidence may cause unnecessary social division and erode public trust, predisposing to stigma.	Siracusa Principles (necessity and proportionality of rights restrictions)[335]; International Covenant on Economic, Social and Cultural Rights Article 12 (right to health) and Article 15 (scientific progress)[334]; WHO guidance (minimising social harm)[331].
9. Psychosocial support should be accessible to affected populations and frontline workers as part of outbreak management.	Psychosocial wellbeing is a critical component of health and plays an important role in reducing the internalisation of stigma.	WHO Constitution (benefits of medical/psychological knowledge)[336]; WHO guidance (reintegration)[331]; WHO Framework on Integrated People-Centred Health Services[333]; UDHR Articles 22 and 23 (social protection, fair work).[326]

D.10 Recommended stigma reduction interventions

The following appendix contains the recommended stigma reduction interventions for each outbreak phase. The final page contains interventions discussed for which no recommendation was made.

Details of recommended interventions

A1. We recommend providing stigma-sensitive training to service providers who interact with affected individuals, including providers outside health settings.	
Strength of recommendation	Strongly in favour
Certainty of evidence	Low
Implementation notes	Training content may cover confidentiality, preferred terminology, the negative impacts of stigma, and cultural sensitivity. Training should be integrated into established health- or service-related curricula to optimise uptake and feasibility, particularly in resource-limited settings. The intervention is expected to have maximum benefit if delivered to all interacting with individuals seeking care or involved in quarantine, treatment, or burial. This includes pharmacists, herbalists, interpreters, faith-based care providers, veterinary staff, public health practitioners, and law enforcement officers, who are often first points of contact. Training modalities that have been effective in non-outbreak infectious disease contexts include role-play, lived experience testimonies, facilitated discussions, and self-guided training and assessment (often in combination). This intervention is strongly recommended despite limited evidence in outbreak contexts due to concerns about high risk of harm if not implemented. This is on the premise that inaction (i.e. business-as-usual) would perpetuate provider-related stigma, contributing to care-seeking hesitancy.
Summary of evidence and considerations	There is no direct empirical evidence from outbreak settings on the impact of stigma-sensitive training for service providers, but moderate- to high-quality systematic reviews from non-outbreak infectious disease contexts.[155,225,310] Gronholm et al. 2021[225] suggest that information provision and skills-based approaches can reduce provider-based stigma. Studies have predominantly focused on healthcare workers. One study on police officer training for mental health found that role-play with actors reduced negative behaviours and was cost-effective.[337] Stakeholder interviews and open-text survey responses supported the relevance of such training for a broad range of providers and highlighted its potential to improve health-related interactions. A qualitative study of Ebola response teams noted that collective pre-deployment training improved team competence.[320] The intervention is considered acceptable, with low intrusiveness, and likely to increase health equity. Its feasibility is dependent on the availability of skilled educators, proactive leadership, and sufficient frontline worker time capacity.

A2. We recommend including stigma awareness as a component of health education initiatives for children and adolescents, particularly when an outbreak may affect these age groups.

Strength of recommendation	Strongly in favour
Certainty of evidence	Low
Implementation notes	This can include interactive activities (e.g. simulations) and lived experience narratives (e.g. video storytelling, books, guest speakers) and may be incorporated into school curricula. The intervention should be tailored to highest risk age categories and developed in consultation with/led by young people of the targeted age group. This intervention is strongly endorsed by the expert panel despite limited evidence due to concerns about a high risk of harm if not implemented (business-as-usual as comparator) including loss of education for affected children.
Summary of evidence and considerations	There is very low certainty empirical evidence for this intervention from a single qualitative study in an outbreak setting, which reported that school leadership encouraging support for children recovered/recovering from Ebola disease was perceived to improve reintegration.[227] This is supported by indirect evidence from two low- to moderate-quality systematic reviews in non-outbreak infectious disease contexts, which found that child-focused stigma reduction interventions (particularly those using educational and interactional techniques such as youth-led sessions, printed comics, and video storytelling) were associated with improved peer attitudes and reduced avoidance behaviours, especially when framed as life skills education and supported by school leadership.[162,312] Stakeholder interviews and open-text survey responses indicated support for school-based engagement, especially when children are affected by the illness, and during reintegration after illness. Respondents described harmful responses by peers and teachers when affected children returned to school and suggested that schools be further considered in outbreak planning. These interventions are generally considered acceptable with low intrusiveness. While development of materials and mobilisation of educators may require additional resources, integration into existing school health education programmes may enhance feasibility. Evidence of cost-effectiveness is limited, but previous similar interventions have been delivered at relatively low cost.[162]

A3. We recommend pre-designing psychosocial support interventions that can be delivered under strict infection control measures.

Strength of recommendation	Strongly in favour
Certainty of evidence	Moderate
Implementation notes	Most supporting evidence is in relation to video and online services or resources. However, non-digital alternatives suggested and tested by stakeholders include radio or phone communication between psychosocial support staff and people receiving care, and training psychosocial support staff on infection prevention and control as part of outbreak preparedness to allow them to provide support under strict infection control conditions. The latter approach should include adequate budget and supervision, pre-designed training modules, and staffing plans to reduce reliance on ad hoc measures or underprepared teams. Implementation should build on pre-existing structures where possible. In resource-limited settings, interventions could include pamphlets or training other affected community members to deliver psychosocial support. The WHO Centre for Health Development[338] provides further resources to guide integration of Mental Health and Psychosocial Support Services into crisis and disaster management structures during each outbreak phase.
Summary of evidence and considerations	There is moderate certainty evidence from two COVID-19-related RCTs that digitally administered psychosocial support resources are effective in reducing perceived social stigma and internalised/self stigma for those with the illness or a demographic/geographic association.[250,251] This is supported by indirect evidence from non-outbreak infectious disease contexts, which suggest that a wide range of psycho-educational and social empowerment approaches are effective at mitigating self stigma, including individual and group-based interventions.[225,308,316] From available data, these interventions appear to mostly be effective in the short term (<1 month).[251] Stakeholder interviews offered support for psychosocial interventions, but highlighted the importance of preparedness, training, and supervision. Surveys across three countries indicated varying support for increased psychosocial services (75%, 63% and 41% of respondents supportive in Uganda (Ebola disease), Bangladesh (Nipah virus disease) and UK (mpox) respectively, although this may be informed by existing support services. Stigma associated with seeking psychosocial support may limit uptake in some settings and cost and feasibility is expected to vary depending on the number of people affected by the outbreak, specific technology, and human resource requirements.

A4. We suggest facilitating community dialogues about relevant infectious diseases and stigma in outbreak-prone areas as part of outbreak preparedness.	
Strength of recommendation	Conditional support
Certainty of evidence	Very low
Implementation notes	This may be implemented through training and funding community health teams or adding stigma as a discussion topic for existing community engagement work. Discussions can cover general topics like germ theory, personal protective equipment, vaccines, and ways to care for others without physical contact. For example, in Bangladesh, the Bangladesh Rural Advancement Committee's Water, Sanitation, and Hygiene programme trained community health workers to lead regular household visits and courtyard meetings.[339] There is an opportunity to incorporate stigma reduction, such as facilitating contact with people with lived experience of outbreaks, into these types of initiatives. This intervention is conditionally supported due to limited evidence but anticipated net benefit. Further evaluation in outbreak contexts is needed.
Summary of evidence and considerations	There is no direct empirical evidence from outbreak settings on the impact of community dialogues on stigma, but stakeholder interviews and survey responses suggest community-led education may help address fear and mistrust that often drive stigma. Indirect evidence from low- to moderate-quality systematic reviews in non-outbreak infectious disease contexts suggests that community-based educational interventions can reduce social stigma, but caution that incomplete or poorly delivered messages may reduce effectiveness or inadvertently reinforce stigma.[253,312,315] A study on Nipah virus communication in Bangladesh found that participatory, image-based communication improved public understanding and trust in prevention messages.[323] Stakeholder interviews highlighted the perceived value of pre-outbreak engagement, with community dialogues viewed as more effective than top-down messaging campaigns. Open-text survey responses were similarly supportive. The intervention is considered generally acceptable, though its intrusiveness may vary depending on implementation. Feasibility is dependent on funding, availability of trained personnel, and existing community health and engagement structures, with no direct evidence on cost-effectiveness. While the intervention may help build trust and reduce social stigma, conclusions remain limited by the lack of direct empirical evidence.

A5. We suggest incorporating person-centred features into personal protective equipment design and protocols to minimise depersonalisation.	
Strength of recommendation	Conditional support
Certainty of evidence	Very low
Implementation notes	Where personal protective equipment (PPE) use is necessary, simple adjustments such as attaching names or faces can help maintain a sense of personhood and emotional connection, especially in high-barrier care environments. The PPE Portrait Project, which involved Ebola outbreak responders wearing portrait photos on their protective suits, is an example that illustrates how small design changes to outbreak protocols can support more person-centred care.[340] PPE should still be used judiciously, with decisions grounded in infection risk rather than fear. This intervention is conditionally supported due to limited evidence but anticipated benefit and low likelihood of harm. Further evaluation is needed.
Summary of evidence and considerations	There is no direct empirical evidence from outbreak settings evaluating the stigma impact of incorporating human-centred design features into PPE. However, stakeholder interviews and survey responses suggest that depersonalisation associated with PPE use may contribute to stigma and reduce quality of care. Indirect evidence from a moderate-quality systematic review in non-outbreak infectious disease contexts highlights the importance of effective patient-provider communication in facilitating health interventions and reducing barriers to care.[310] Stakeholders described the use of names on PPE and avoiding over-use of PPE as a feasible and low-cost way to support more human interactions in high-barrier environments. Acceptability was high amongst stakeholders, and the intervention is considered minimally intrusive. One community respondent highlighted the importance of enabling physical caregiving through adequate protective equipment. Feasibility may vary depending on design elements and supply chain factors, but simple adaptations are likely to be implementable in most settings. Although cost-effectiveness analyses have not been published, minimal-resource adaptations are likely to be inexpensive.

A6. We suggest collaborating on preparedness activities with community members affected by previous outbreaks or illnesses with transferable learnings.

Strength of recommendation	Conditional support
Certainty of evidence	Very low
Implementation notes	This may include working together through strategy and communication development meetings, simulation exercises, and policy consultations. For example, people living with HIV often have insights that are transferable to other conditions such as mpox. People affected by one outbreak are also often interested in helping to prepare for subsequent outbreaks of the same disease. In preparing for future Zika outbreaks, for instance, it may be helpful to engage women's health and disability rights groups that were involved in the response during the epidemic in Brazil.[341] It is important to provide sufficient resources and training to community volunteers to facilitate involvement. Included community members should represent a diversity of lived experiences, and include individuals with marginalised identities. This intervention is conditionally supported due to limited evidence but anticipated net benefit. Further evaluation in outbreak contexts is needed.
Summary of evidence and considerations	There is no direct empirical evidence from outbreak settings on this intervention, but stakeholder interviews described benefits such as enhanced trust, more relevant interventions, and institutional memory. Indirect evidence from a moderate-quality systematic review in the context of HIV noted that while trained community members found involvement in response coordination challenging, they also found the experience rewarding.[312] An additional methodologically sound qualitative study from a previous Ebola outbreak highlighted barriers to effective engagement, including limited consultation, poor communication, under-compensation, and inadequate institutional support.[321] Stakeholders described the involvement of affected communities in preparedness activities as valuable, both for drawing on past experiences and for avoiding repeated mistakes. Acceptability was considered high, though potential harms include overburdening participants and increased identifiability. Feasibility depends on adequate human resourcing, funding, and support structures to avoid reliance on goodwill. Integration may be enhanced through partnerships with community-led organisations. The intervention may support health equity and improve the relevance of outbreak preparedness strategies, but conclusions are limited by the very low certainty and indirect nature of available evidence.

B1. We recommend embedding stigma reduction messages in public health education and risk communication efforts.

Strength of recommendation	Strongly in favour
Certainty of evidence	Moderate
Implementation notes	Information provision is often suggested and widely used to address stigma, but evidence indicates that improving knowledge about an outbreak does not necessarily reduce stigma unless combined with stigma-specific messaging. Stigma reduction messages can be included in daily briefings, posters, and social media, or can be disseminated through partnership with local leaders and representatives. Content can foster a sense of solidarity or collectivism, or emphasise reciprocity (e.g. "treat others as you would like to be treated") and suggest ways to safely support affected individuals. Consistency across formats is helpful for reinforcing key messages. These key messages should be shared with the media.
Summary of evidence and considerations	There is moderate certainty evidence from two COVID-19 RCTs that embedding stigma reduction messages into public health campaigns can reduce fear and stigmatising attitudes compared to no intervention or general health information alone.[244,245] Low certainty qualitative evidence describes targeted community-led efforts by religious leaders and community elders to support the reintegration of people recovered from Ebola disease .[227,306] Indirect systematic reviews support the use of public education and mass media to reduce stigma but in many cases did not specify if this education is about the disease, associated stigma, or both.[155,225,253,312,316–318] The reviews note that messaging is more effective when consistent and developed with attention to local beliefs. Non-interventional studies found that contradictory messaging contributed to confusion and stigma and suggested that visual formats might improve communication.[195] Drawing on experiences of the SARS outbreak, a qualitative study recommended that messages be delivered through trusted local channels to supplement broader media campaigns.[29] Stakeholders interviewed noted that factual information alone is often insufficient and, in some cases, may worsen stigma. Interviewees highlighted the value of involving trusted, locally embedded messengers and incorporating empathetic messaging. Public education and stigma reduction messaging were the most supported stigma reduction interventions across the three survey contexts.

B2. We recommend facilitating public engagement with affected individuals' experiences.	
Strength of recommendation	Strongly in favour
Certainty of evidence	Moderate
Implementation notes	Improved public understanding of how people are affected by the outbreak and associated stigma can be facilitated through digital technology, arts-based approaches, or public testimonies. A particularly promising method is participatory video, in which affected individuals are taught how to create short documentaries or films about their own experiences, which are then shared publicly. Other possible formats include poetry, theatre, newspaper, or community radio. These interventions are considered helpful for fostering empathy and humanising the outbreak. Evidence suggests that 'social contact' focused interventions (i.e. interacting with people from the stigmatised group) are most effective under conditions of equal status among participants, cooperative interaction, institutional support, and when they counter assumptions or stereotypes.[342] These interventions may involve individuals with the illness, those who have recovered, or their family members, and remain relevant during the recovery phase. Explicit safeguards—including informed consent, clear opt-out mechanisms, and privacy protections—are needed to mitigate risks of re-traumatisation or social repercussions. Interventions should make use of pre-existing engagement and communication channels when possible.
Summary of evidence and considerations	There is low certainty evidence from one RCT showing that a brief video portraying a person with COVID-19 discussing their experiences reduced public stigma.[244] Very low certainty evidence from a qualitative study on Ebola disease found that survivor-led peer education improved reintegration and reduced stigma more effectively than top-down campaigns.[227] Indirect evidence from moderate- to high-quality systematic reviews in non-outbreak disease contexts supports participatory video, testimonials, and arts-based formats as effective approaches to foster empathy, shift attitudes, and reduce stigma at community and individual levels.[155,225,308,312,316,317] Stakeholder interviews highlighted the role of storytelling and representation in empowering affected individuals. Survey responses across three settings showed public support for hearing directly from survivors, with some suggesting this approach was more effective than health worker messaging. While generally feasible and low-cost, interventions require appropriate planning, participant safeguards, and compensation. Feasibility may vary depending on format and setting.

B3. We recommend offering accessible psychosocial support and resources to those affected by the outbreak, such as remote services during isolation.	
Strength of recommendation	Strongly in favour
Certainty of evidence	Moderate
Implementation notes	Support should extend to frontline workers, carers, household members, and others at risk of stigma due to their work, identity, or proximity to mitigate self/internalised stigma. This intervention is likely most effective when implemented early and repeated since the available research suggests a short-term (<28 day) effect.[251] While most of the available evidence is in relation to online resources, the intervention's chosen modality should be culturally aligned and make use of pre-existing structures as far as possible. The intervention may be delivered by mental health professionals (e.g. psychiatrists, psychologists), community members with specific training (e.g. lay counsellors, peer support) or be an online or printed resource. Resources may include content on managing emotional distress or the perceptions of others. The support/resources should be accessible discretely so as to avoid additional stigma often associated with seeking psychosocial support. Effort should be made to ensure the service is accessible to marginalised groups. The WHO Centre for Health Development[338] provides further resources to guide integration of Mental Health and Psychosocial Support Services into crisis and disaster management structures during each outbreak phase.
Summary of evidence and considerations	There is moderate certainty evidence from two RCTs showing that brief, digitally delivered psychosocial interventions can reduce perceived outbreak-stigma in the short term.[250,251] These included an online programme for those recovering from COVID-19 and a writing-based intervention that reduced perceived COVID-19 discrimination among individuals returning from a high-risk area. Indirect evidence from moderate- to high-quality systematic reviews in non-outbreak infectious disease contexts supports a range of psychosocial support approaches, including peer-led counselling, lay provider interventions, and group-based formats, for reducing self stigma and related outcomes.[155,225,308,312,317] Stakeholder interviews indicated high acceptability, especially when support is delivered early, confidentially, and tailored to the affected group. Community support across three contexts varied substantially but may be due to differing existing support mechanisms across settings. In some contexts, accessing psychosocial services may itself be stigmatised, which could limit uptake. Feasibility is likely to vary depending on access to trained personnel and available technology, but digital platforms may improve scalability.

B4. We recommend co-designing, adapting and implementing stigma awareness initiatives for the local context with affected community members, including people with lived experience of the illness.

Strength of recommendation	Strongly in favour
Certainty of evidence	Moderate
Implementation notes	This includes mass media campaigns. There is a risk of co-design being rushed, tokenistic, and reliant on goodwill. For it to be meaningful, community engagement must be funded, provide necessary training and logistical support, allow time for genuine input, and include diverse contributors, not just those who are most visible or familiar. When possible, and of interest to affected community members, these interventions should also be led by people with lived experience. Participation should be voluntary and include discussion of potential risks, especially in relation to visibility and identifiability.
Summary of evidence and considerations	There is moderate certainty evidence from two qualitative studies suggesting that co-designed public health messaging led by affected community members can reduce outbreak-stigma.[217,227] In the UK mpox response, community organisations helped design messaging using local colloquialisms and humour to improve reach in the context of post-COVID-19 public health fatigue.[217] In Sierra Leone, local development of stigma reduction efforts with community leaders and Ebola survivors was found to be effective in facilitating reintegration.[227] Indirect evidence from moderate- to high-quality systematic reviews supports participatory approaches, emphasising the importance of tailoring messaging to local beliefs and practices, building on community-proposed strategies, and ensuring accessibility to marginalised groups.[225,253,308] Non-interventional studies supported co-designed approaches, though challenges were noted—including rushed timelines, lack of funding, and reliance on unpaid or overstretched community members.[29,321,322] Stakeholder interviews emphasised the need for trusted messengers, community-led framing, and adaptation to different levels of health literacy. Community surveys indicated high cross-contextual support for more thoughtful messaging and demonstrated a readiness to provide input. While feasibility is generally high with sufficient planning, sustainability requires coordination, resources, and time allocation for meaningful inclusion. Ensuring messages reach communities more effectively could save communication-related costs.

B5. We suggest facilitating peer support opportunities led by people with lived experience.

Strength of recommendation	Conditional support
Certainty of evidence	Low
Implementation notes	Peer-led support may help reduce feelings of social isolation during recovery. Training and sustained support structures are important to ensure peer mentors are equipped and not overburdened. Participation in peer led psychosocial interventions should be voluntary and informed by local and cultural norms related to care and support. These may be embedded within the clinical setting. This intervention is conditionally supported due to limited evidence but anticipated net benefit. Further evaluation in outbreak contexts is needed.
Summary of evidence and considerations	There is no direct empirical evidence from outbreak contexts on the impact of peer-led support opportunities. Indirect evidence from moderate-quality systematic reviews in non-outbreak infectious disease settings suggests that peer-led interventions may help improve self-esteem and facilitate social reintegration. These effects were linked to reduced self/internalised and anticipated stigma.[308,312] Reviews highlighted the importance of adequate training and supervision to ensure peer mentors are well-prepared and not overburdened. Stakeholder interviews offered strong endorsement of peer-led support, particularly when grounded in shared experience and delivered in trusted spaces such as community settings. Examples included survivor associations continuing to provide outreach and education post-outbreak, and peer support embedded in healthcare encounters. Acceptability is considered high when opportunities are voluntary and culturally aligned. Feasibility may depend on training, supervision, and integration with formal systems, but indirect evidence supports sustainability if well embedded.

B6. We suggest against introducing community protection bylaws that impose fines for stigmatisation of affected persons.

Strength of recommendation	Conditionally against
Certainty of evidence	Very low
Implementation notes	Bylaws or penalties have been introduced in some outbreak contexts to deter discrimination against recovered individuals. Concerns include erosion of trust, social consequences for families, and reinforcement of stigma, particularly if law enforcement is involved. This approach has raised concerns about the use of coercion rather than addressing underlying drivers of stigma, such as fear, misinformation, or mistrust of authorities. Instead, non-punitive structural changes and community support should be prioritised. Non-police actors such as village health teams or trained community representatives may be better positioned to engage the public. These community protection efforts should be community-initiated, rights-respecting, proportionate, and supported by education and dialogue. This recommendation does not apply to instances of discrimination that are already prohibited under existing human rights and legal frameworks.
Summary of evidence and considerations	There is very low certainty evidence from a qualitative study in Sierra Leone suggesting that community-developed protection bylaws may help reduce Ebola stigma when locally led and integrated into broader efforts.[306] However, in interviews stakeholders raised concerns about punitive approaches, especially when implemented by police or imposed without local consultation. While community members may respond positively to fair and educational enforcement, punitive or culturally inappropriate approaches risk backlash and long-term harm. Findings from systematic reviews of non-outbreak infectious disease contexts highlight similar tensions.[225,312,317] Legal protections may support justice in some contexts, but punitive or coercive approaches may worsen stigma, particularly where trust in authorities is low. Public support for legal fines or sanctions was low across all survey settings, reinforcing the need for caution.

B7. We support further research on the stigma impact, feasibility, and acceptability of community-based quarantine, isolation, and care.

Strength of recommendation	Research only
Certainty of evidence	Very low
Implementation notes	Community quarantine, isolation, and care may be considered more acceptable in some contexts than distant institutional services, especially where institutional mistrust or stigma already exist. However, these approaches require adequate community preparation, including suitable physical and social conditions. Appropriateness may also vary substantially depending on the pathogen. This intervention may involve facility-based care within the community or home-based care, with either requiring further assessment. Considerations need to be made for safety risks, increased household stigma, feasibility for people without traditional homes, and undue burden placed on households in the case of home-based care, particularly in low-resource or overcrowded settings.
Summary of evidence and considerations	There is no direct empirical evidence from the outbreak-related systematic review on community-based quarantine or care. A study in the context of Ebola disease in the DRC suggests community-based quarantine for close contacts may be non-inferior for disease control but the impact on stigma was not evaluated.[343] Stakeholder interviews highlight both potential benefits and risks. In some settings, institutional quarantine was associated with fear, mistrust, and avoidance behaviours, including escape attempts. By comparison, community or home-based approaches were described as more acceptable, fostering dignity and trust, particularly when individuals and families were supported to monitor for symptoms. In contrast, some interviewees expressed concern that, without sufficient preparation or support, home-based quarantine could increase psychosocial stress, place vulnerable family members at risk, or result in delayed care-seeking and ineffective infection control. Practical constraints, such as overcrowding, lack of sanitation, and subsistence living conditions, were flagged as major barriers. No affected community survey responses addressed this intervention. Overall, home-based quarantine may be less stigmatising but further research into the necessary preconditions is warranted.

C1. We suggest implementing initiatives that help people who have recovered reintegrate into their households, workplaces, schools, religious practices, and other community activities.	
Strength of recommendation	Conditional support
Certainty of evidence	Very low
Implementation notes	This includes sharing clear information on recovery timelines and guidance on safe return to work, school, and other social settings. This information should be made publicly available and provided directly to recovered individuals in a format that is easy to share with others (e.g. printed leaflets, text messages, or a website link for employers or schools) and to contexts such as schools and workplaces where appropriate. Initiatives may also include support and focused education efforts from psychosocial support staff where context-appropriate. This intervention is conditionally supported due to limited evidence but anticipated net benefit. Further evaluation in outbreak contexts is needed.
Summary of evidence and considerations	Although no direct empirical evidence was identified from outbreak contexts, qualitative and indirect evidence indicates that reintegration initiatives can mitigate stigma. Gronholm et al.'s review[225] found workplace anti-stigma interventions consistently improved employees' supportive behaviours in other disease contexts, and a review by Driedger et al.[310] highlighted the social and economic vulnerability of individuals facing stigma, including lost income and exclusion from services. Stakeholder interviews described the role of psychosocial teams in reassuring families and communities, the use of recovery leaflets and web pages to support re-entry into work or school, and direct engagement with employers to encourage acceptance of recovered individuals. These actions were reported to promote community reacceptance. While reintegration initiatives are generally considered acceptable, feasibility depends on intersectoral coordination and the development of accessible, context-appropriate materials. The net economic implications are expected to favour the intervention, given that preventing recovered individuals from returning to work or education results in substantial financial losses. It may be seen as minimally to moderately intrusive depending on mode of delivery.

C2. We suggest including assessment of psychosocial wellbeing as part of integrated follow-up care for people who have recovered and offering referral to longer-term support services.

Strength of recommendation	Conditional support
Certainty of evidence	Very low
Implementation notes	Psychological and social harms often persist well beyond clinical recovery. Recovered individuals have reported feelings of isolation, distress, and suicidal ideation related to ongoing stigma, loss of livelihood, and lack of community acceptance. Follow-up services should include routine screening for psychosocial needs and clear referral pathways, with informed consent, to ongoing support. This is particularly important in contexts where reintegration is noted to be difficult due to stigma. Physical causes for distress or psychological disturbances should be excluded first and the legal and ethical implications of referral should be carefully considered. Follow up services should be integrated into routine care as far as possible to avoid further othering and discrimination. This intervention is conditionally supported due to limited evidence but anticipated net benefit. Further evaluation in outbreak contexts is needed.
Summary of evidence and considerations	There is no direct empirical evidence from outbreak settings related to psychosocial support but stakeholder interviews emphasised the need for follow-up care that includes assessment of psychological and social wellbeing. Stakeholders described the psychological toll of ongoing stigma following recovery, including cases of suicidal ideation, financial hardship, and persistent social exclusion. Several stakeholders highlighted the importance of routine psychosocial screening and referral as a way to identify and address stigma-related distress, drawing on models from HIV care where such systems are more commonly integrated into follow-up. Survey responses showed mixed support for more psychosocial support across settings (75% in Uganda, 63% in Bangladesh, 41% in the UK), although this is likely informed by the current available support. The intervention aligns with human rights principles and is likely to be acceptable if services are voluntary and confidential. Feasibility will depend on the availability of trained personnel and existing service infrastructure, though referral points will often already exist. The implementation suggestion to integrate follow up services into routine care is supported by a study in Hong Kong in which SARS survivors reported that separate entrances reconstructed stigma against them and made them feel as if they were still infectious, and that attending psychiatric clinics to receive support labelled them with an additional form of stigma.[307]

C3. We suggest documenting, robustly evaluating, and publishing stigma reduction efforts.	
Strength of recommendation	Conditional support
Certainty of evidence	Very low
Implementation notes	Stigma reduction efforts are rarely evaluated during outbreaks, limiting opportunities for shared learning. Evaluation should be planned in advance and embedded into response activities. Mixed methods can help capture both outcomes and context. Implementation studies can assess outcomes such as feasibility, acceptability, and fidelity. Designs such as stepped wedge cluster trials can support evaluation of phased, real-time interventions. It is often helpful to have pre-prepared and or pre-approved protocols for assessing stigma reduction in outbreak responses as ethical review processes can be slow and protocols for testing biomedical interventions may take priority during an outbreak, limiting the ability to evaluate stigma reduction efforts. Publications should ideally be made freely publicly available. Evaluation reports should include adequate details about the context, intervention, and evaluation tools or methods used. This intervention is conditionally supported due to limited evidence but anticipated net benefit. Further evaluation in outbreak contexts is needed.
Summary of evidence and considerations	The limited direct empirical evidence from outbreak settings evaluating stigma reduction interventions throughout highlights this important gap. Multiple systematic reviews and stakeholder interviews consistently emphasise that the lack of evaluation limits opportunities to identify effective approaches and improve future responses.[225,312,315–317] These reviews have noted shared challenges across infectious disease contexts such as unvalidated outcome measures, inconsistent study designs, limited assessment of long-term impact, and a lack of research from low- and middle-income settings. One non-interventional analysis highlighted the failure of existing monitoring systems to capture real-time stigma patterns, particularly at the intersection of race and health.[324] Stakeholders interviewed stressed the importance of embedding evaluation into outbreak responses to understand stigma persistence and improve intervention design. While no harms were identified, acceptability depends on transparent, voluntary data collection and protection of confidentiality. Evaluation is likely to improve equity and efficiency by informing scalable, evidence-based approaches. Feasibility depends on research capacity and resourcing but can be enhanced through integration into response.

C4. We support further research on the effectiveness, acceptability, and potential harms of facilitating visible contact between response workers and recovered persons.	
Strength of recommendation	Research only
Certainty of evidence	Very low
Implementation notes	Small, symbolic gestures from trusted figures (e.g. local representatives, leaders or healthcare workers), such as sitting together, shaking hands, or walking side by side with recovered individuals, is anecdotally reported to help address fears, contribute to community confidence in a person's recovery, and support reintegration. However, there are also potential risks including gender and cultural sensitivities around physical contact and concerns about unwanted attention and discomfort. Further research is required to robustly explore the benefits and risks of this intervention. Alternative formats may include, for example, healthcare workers entering recovery areas or former treatment facilities without PPE to indicate safety. When implemented, physical interactions should always be voluntary and carried out with the individual's consent. Their impact is expected to be greatest when combined with broader community engagement and local leadership.
Summary of evidence and considerations	There is no direct empirical evidence from the outbreak-related systematic review. Stakeholder interviews from the context of Ebola disease suggest that visible, voluntary gestures by trusted figures, such as shaking hands or sitting beside a recovered person, can help reduce fear, demonstrate safety, and support social reintegration. These actions were described as meaningful symbols of acceptance that influenced community perceptions. A survey respondent similarly noted that endorsement by health workers may be more trusted than messaging from the recovered person alone. The intervention is generally low cost and can be integrated into existing communication or psychosocial activities. Acceptability appears high when gestures are consensual and culturally appropriate. However, risks include unwanted attention, discomfort, or breaches of privacy, particularly if actions are not planned with the individual. Anecdotes are focused on Ebola disease, and broader applicability remains uncertain.

C5. We support further research on the effectiveness, acceptability, and potential harms of recovery celebrations.	
Strength of recommendation	Research only
Certainty of evidence	Very low
Implementation notes	Symbolic or celebratory practices such as homecoming events or visible recognition of survivors have been used to support social reintegration following outbreaks, although no formal evaluations of these practices have been found. Examples include symbolic survivor walls, music, dancing, or small homecoming gatherings, often led by families or health workers. These practices may help shift the public focus from loss to recovery. However, safeguards would need to be in place to ensure participation is voluntary, and decisions about format and timing should rest with the recovered individual. Planning must consider the risk of unwanted visibility, potential pressure to participate, and sensitivity to those who have experienced loss. Celebration and mourning may coexist in affected communities, and public events must reflect this complexity. These interventions should ideally be led by affected community members and people with lived experience. These celebrations may also include celebrating healthcare workers. To date these interventions tend to be informally documented and the effectiveness and harms have not been robustly evaluated. Further research is needed to evaluate the efficacy of recovery celebrations to reduce stigma, as well as their feasibility, acceptability and applicability in different contexts.
Summary of evidence and considerations	Stakeholder interviews described examples of recovery celebrations, such as homecoming events, survivor walls, and community songs used in the Ebola disease and COVID-19 response to mark recovery and support reintegration. These practices were reported to have a positive psychological and social impact in some settings and may contribute to reducing stigma through public affirmation of safety and belonging. One respondent from Uganda suggested a national survivor celebration day. These accounts suggest that, in some contexts, celebration may help foster community support and counter fear-based exclusion. However, the potential risks include unwanted visibility, pressure to participate, or emotional discomfort. Celebrations may be inappropriate or distressing for individuals who prefer a lower-profile return or in communities experiencing active grief. Acceptability is likely to depend heavily on individual preference, timing, and cultural context. No evidence of cost or effectiveness is available beyond anecdotal accounts, and overall certainty remains very low.

Interventions discussed by the expert panel but not included in the final guidelines (no recommendation)

Implementing recovery certificates

Reasons for no recommendation:

- Very low certainty evidence available (both in support and against).
- Concern that blanket cross-outbreak recommendation is not appropriate as may be valuable in some contexts but may also have the capacity to be stigma-inducing or be used as an instrument of bureaucratic exclusion.

Implementing population-wide outbreak control measures to avoid targeted restrictions

Reasons for no recommendation:

- Very low certainty evidence available (both in support and against).
- Considered too outbreak- and context-specific.
- Concern that may be interpreted as recommending against all universal precautions.
- Concerns that, if adopted, stigma shifts to those unable to comply with the measures, e.g. due to disability, environment, or cost.
- Concern that intervention may be interpreted as endorsement of evidence-free application of interventions where they cause no benefit and result in unnecessary costs.

Introducing low-cost reassurance measures such as temperature screening

Reasons for no recommendation:

- Very low certainty evidence available (both in support and against).
- Concerns that such approaches may be appropriate in specific circumstances but in others undermine the value of evidence-based interventions.
- Concerns about low evidence of effectiveness of temperature screening for many diseases.

Providing material resources or financial support to individuals with the illness/recovering or to the families of the deceased

Reasons for no recommendation:

- Very low certainty evidence available (both in support and against).
- Insufficient evidence or rationale for stigma reduction, and concern about potential for furthering community divisions.
- Considered more appropriate for outbreak-specific discussion rather than cross-outbreak recommendations.

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