

The (Re)-emerging And ePidemic Infectious Diseases (RAPID) Stigma Scales: a cross-outbreak scale development and psychometric validation study



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Reducing stigma during infectious disease outbreaks is crucial for delivering an effective response. However, no validated stigma scales exist for use across outbreaks, and outbreak-specific scales are developed too slowly to guide timely interventions. To enable more real-time monitoring and mitigation of stigma across outbreak contexts, we developed and validated the (Re)-emerging and ePidemic Infectious Diseases (RAPID) Stigma Scales. Field testing and psychometric validation were conducted in communities affected by Ebola disease in Uganda, mpox in the UK, and Nipah virus disease in Bangladesh. Content validity was established through cognitive interviews and expert Delphi scoring. 1008 respondents were included across the three countries. The final RAPID Community Stigma Scale (12 items) captures initial social stigma, provider or authority-related stigma, structural stigma, and enduring social stigma. The RAPID Self Stigma Scale (4 items) is unidimensional. Both scales were found to have robust psychometric properties, including content validity, structural validity (factor loadings ≥ 0.6), and reliability (ordinal alphas 0.79–0.92). High scores on both scales predicted an increased hesitancy to report symptoms and seek care. The RAPID Stigma Scales are validated tools for real-time assessment of stigma across outbreak settings, enabling responders to design targeted interventions to improve health outcomes and promote equitable care.

Introduction

Stigma is a pervasive challenge in outbreaks of new and re-emerging infectious diseases.^{1,2} It repeatedly hampers timely care-seeking, discourages participation in outbreak research, and hinders community reintegration, as seen in outbreaks of COVID-19, Ebola disease, mpox, Zika virus disease, Middle East respiratory syndrome coronavirus, and Nipah virus disease.^{1–4} These effects, in turn, worsen health outcomes and complicate efforts to control outbreaks.^{1,2} For example, stigma associated with Ebola disease has been shown to exacerbate disease transmission by encouraging the concealment of symptoms and unsafe burial practices.⁵ Addressing stigma is essential, not only to improve individual and community wellbeing, but also as a public health priority.

Stigma occurs when an individual or a group are disqualified from full social acceptance due to an attribute, in this case association with an illness, perceived as shameful or discrediting in their society.⁶ Stigma can be broadly categorised into external (or community) stigma, which is driven by the attitudes of others, and self stigma, which arises when individuals internalise these perceptions.⁷ In outbreak contexts, external stigma can be further divided into initial social stigma (related to social interactions at the time of the illness), enduring social stigma (related to social interactions following recovery), provider or authority-related stigma (eg, from health-care workers or leaders), and structural stigma (which is institutionally driven or systemic).^{8,9}

Despite the profound public health and community effects of stigma, challenges remain with regards to the validity and transferability of existing tools for assessing stigma during outbreaks.⁹ Stigma scales take time to develop and validate, meaning they are often unavailable during the active phases of an outbreak.⁹ For example, the median time from the start of an outbreak to the publication of a relevant stigma scale is 2 years.⁹

Key messages

- Stigma associated with infectious disease outbreaks frequently complicates outbreak control and has lasting socioeconomic effects on affected individuals and communities
- No measure has been designed and tested for assessing stigma across infectious disease outbreaks
- This study presents the RAPID Community and Self Stigma Scales, designed for new and re-emerging infectious diseases
- The RAPID Community and Self Stigma Scales showed strong psychometric properties across three outbreak contexts: mpox, Ebola disease, and Nipah virus disease
- This study offers researchers, practitioners, and policy makers a robust, adaptable tool for real-time stigma assessment in outbreaks, supporting data-driven strategies to reduce stigma and enhance public health responses

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Although there are several outbreak-specific scales developed for the recovery phase of outbreaks, such as those related to survivors of Ebola disease,^{10–16} timely stigma assessment during the active phase remains difficult. Without rapid assessment, early opportunities to reduce stigma are missed because public health responses cannot be tailored to address the specific stigma dynamics as they emerge during outbreaks. Additionally, most tools are either highly disease-specific or do not have validation across diverse outbreak settings, further restricting their utility in guiding stigma mitigation efforts in real time.⁹

Although most existing scales have a narrow focus, manifestations of stigma have been noted to be similar across diseases and geographical regions,¹⁷ creating an opportunity for transferable solutions. Developing cross-cutting stigma scales, which avoid disease-specific silos, has long been recommended.¹⁷ This approach has been successfully implemented for chronic diseases,¹⁸ but there have not yet been similar efforts for acute infectious disease outbreaks.

Psychometrically validated, widely used scales have proven to be powerful tools for understanding stigma linked to other health conditions, including HIV and mental health conditions.^{19–22} These tools have informed the design and evaluation of targeted stigma reduction interventions, strengthening the evidence base for future public health responses.^{19–22} However, such scales are poorly suited to acute infectious diseases, which are characterised by distinct phases, including active illness and post-recovery reintegration, and infection prevention measures, such as physical distancing or quarantine. This poor fit underscores the need for tools specifically designed and validated to address the unique challenges of acute infectious disease settings, ensuring that stigma interventions are appropriately directed.

To address this need, we developed and validated the (Re)-emerging and ePidemic Infectious Diseases (RAPID) Stigma Scales. These scales are brief and transferable across a wide range of outbreak contexts. By addressing the limitations of existing tools, we provide a readily usable set of tools for stigma detection in outbreaks.

Methods

Study design

The RAPID Stigma Scales were developed and validated in accordance with the best practices put forward by Boateng and colleagues.²³ The methods involved two iterative phases (figure 1).

Phase 1: scale development

The systematic review of existing stigma scales⁹ was followed by in-depth interviews with 34 purposively sampled stakeholders²⁴ with varied outbreak response experience to enhance the scale's usability and applicability across different settings. Insights from these sources, combined with health-related stigma theory,^{6–8,25–27} were used to identify initial domains and potential items (stigma variants considered in scale development are provided in the appendix p 2).

The initial selection and adaptation of items were conducted in discussion with eight members of the core research team, including two community co-investigators and authors. We selected and adapted items based on conceptual relevance, cross-contextual applicability, and simplicity of language. Items were designed to be indirect or distanced from the respondent (ie, phrased in the third person) to reduce social desirability bias and sensitivity, and broaden the sampling frame, in line with stakeholder recommendations (appendix p 3).

Items were refined through two rounds of feedback in a Delphi process with a multidisciplinary panel of experts representing all WHO regions. Ten experts per WHO region, specialising in outbreak response, stigma research, or both, identified through a literature search and institutional networks, were invited to contribute via email.

41 experts contributed to at least one feedback round (appendix p 4). During these rounds, experts scored the clarity, relevance, and comprehensiveness of draft items, survey instructions, and response options on a 4-point content validity index score (eg, relevance scored from 1, meaning not relevant, to 4, meaning highly relevant) and provided qualitative feedback for low scores. The format and items were revised following each round based on consistent feedback (appendix p 5).

The draft scale was translated into Luganda, for use in central Uganda, and Bengali, for use in Bangladesh, following the International Society for Pharmacoeconomics and Outcomes Research guidelines, including forward-back translation and reconciliation.²⁸

Items were further refined through cognitive interviews with community members affected by Ebola disease in Uganda, mpox in the UK, and Nipah virus disease in Bangladesh. These contexts were chosen to ensure applicability across diverse geographical settings and outbreak dynamics, including variations in modes of disease transmission and case-fatality rates. We used a combination of think-aloud and probing methods with the scales iteratively adapted until no confusion or

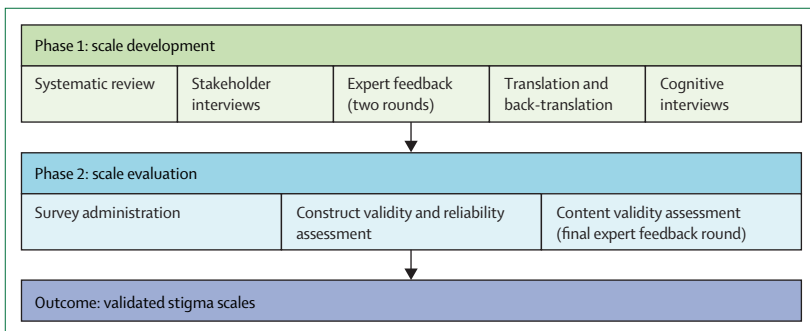


Figure 1: Overview of methods used in development and evaluation of the RAPID Stigma Scales

concerns were identified (appendix p 6). Saturation was reached after 10–16 interviews per site.

Phase 2: scale evaluation

Study population and sampling strategy

We tested the scales' construct validity and reliability in the same three outbreak-affected communities they had been piloted in; namely, the Ebola disease outbreak in Uganda, the mpox outbreak in the UK, and the Nipah virus disease outbreak in Bangladesh. A minimum of 300 respondents were recruited per site, consistent with established recommendations for scale validation, which propose a sample size of ten participants per scale item or 300 participants, irrespective of item number, as the threshold for ensuring stable factor analysis.^{23,29}

We used non-random quota sampling to ensure representation of recovered people, household members and close contacts, health-care workers, outbreak response staff, and other affected community members. Probability sampling was considered, but posed a risk of under-representing the most affected subgroups and would be constrained by logistical challenges, particularly in geographically dispersed and resource-limited settings. Quota sampling ensured inclusion of key populations, particularly those with lived experience of the disease, while addressing these constraints. This approach was deemed appropriate given the study's focus on validating the scale across diverse and heterogeneous affected populations rather than generating broader representative estimates. Respondents were eligible if they were aged 18 years or older, lived in an area affected by the outbreak, were aware of the outbreak of concern, spoke a language the survey was available in, and were able to provide informed consent.

Recruitment and administration

Recruitment and administration methods were tailored to the context of each study site. In the UK, recruitment was conducted online via Prolific, social media, sexual health-care professional networks, and institutional mailing lists of local HIV and LGBTQ+ organisations, as these population groups were considered most affected at the time of survey administration.³⁰ 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 researchers after training, provided by the author group (AP, AC, OK, and KHD). During scale administration, any items that respondents had difficulty understanding were flagged and the reason documented. Surveys were conducted online with Research Electronic Data Capture when feasible, with paper-based forms used in areas with poor internet access. Data collection occurred between April 3 and Sept 11, 2024.

Statistical analysis

We conducted psychometric analyses to ensure that the RAPID Stigma Scales reliably and accurately measured the underlying stigma constructs. All analyses were conducted with R, version 4.4.2 (psych, GPArotation, lavaan, semTools, and survey packages), with statistical significance set at a p value of less than 0.05. The psychometric properties assessed are defined in the appendix (p 7).

Data cleaning and missing data

Data cleaning involved removing ineligible respondents, incomplete surveys, and responses that failed either of the two attention checks in the online version of the survey (appendix p 8). Missing data were minimal ($\leq 0.5\%$ across all variables) and primarily from paper-based forms used in areas with poor internet access. Missingness was handled with listwise deletion for all analyses.

Descriptive and response distribution analyses

We described the study population with standard descriptive statistics, summarising continuous variables with measures of central tendency and variability, and categorical variables with frequencies and percentages. We treated Likert scale responses as ordinal data, and scale mean scores as continuous data. We examined response distributions and flagged items for removal if they met the following predefined criteria: floor or ceiling effects of more than 80%, skewness outside the range of -1 to 1 , absolute kurtosis of more than 7 , adjacent item endorsement frequencies of less than 10% , or inter-item correlations of more than 0.8 (appendix pp 9–10).³¹

Internal construct validity: exploratory and confirmatory factor analyses

We randomly split the dataset 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. We confirmed data suitability for factor analysis with the Kaiser–Meyer–Olkin (KMO) measure and Bartlett's test of sphericity, considering KMO of greater than 0.8 and a significant Bartlett's test ($p < 0.05$) as sufficient evidence of factorability.^{32,33} We conducted EFA with unweighted least squares extraction to account for the ordinal nature of our data, and Promax rotation since factor correlation was anticipated, with the optimal number of factors determined by parallel analysis and the Empirical Kaiser criterion. Items with cross-loadings of greater than 0.3 or communalities of less than 0.4 were removed one at a time and the EFA rerun after each item removal until all items had single factor loadings of greater than 0.4 . 95% CIs for factor loadings were obtained via bootstrapping ($n=1000$) with Procrustes rotation to align factors across resamples.

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See Online for appendix

We performed CFA to confirm the factor structure identified in the EFA, with the weighted least squares means and variance-adjusted estimator, which is appropriate for ordinal data and non-normally distributed data. We evaluated model fit with global fit indices, including the scaled comparative fit index (CFI), root mean square error of approximation (RMSEA), and standardised root mean square residual (SRMR). We also examined residual correlation matrices and modification indices to assess local fit, and considered theoretical justifications to avoid overfitting. We selected the final models based on statistical fit, parsimony, and interpretability.

To assess the effect of non-random sampling, we conducted a weighted CFA for each scale with the survey package. In these sensitivity analyses, sampling weights, based on estimated population sizes for each respondent category, were applied to account for unequal selection probabilities. Fit indices and factor loadings of the weighted and unweighted models were then compared (appendix pp 11–12).

Reliability and external construct validity

We assessed scale internal consistency with ordinal alpha (Cronbach's alpha and hierarchical omega reported in the appendix p 24). External construct validity was assessed through regression analyses testing predefined hypotheses, including relationships between stigma scores and outcomes such as symptom-reporting

hesitancy (multiple linear regression), care-seeking hesitancy (multiple logistic regression), and acceptance of recovered people (multiple logistic regression; appendix p 13), and the relationship between community stigma and self stigma (multiple linear regression). All models controlled for covariates, including age, gender, study site, urban or rural residence, health-care worker status, previous diagnosis, close relationships with recovered individuals, and self-reported understanding of the illness. We excluded multicollinearity by examining variance inflation factors (all were <10).

Content validity

Content validity was initially established through the comprehensive scale development process, including the systematic review, stakeholder interviews, and expert feedback. It was further ensured through the cognitive interviews, which focused on optimising end-user clarity, relevance, and comprehensiveness across study sites. To calculate final content validity index scores, we invited experts who participated in both initial Delphi rounds to complete a final round, rating the face validity, relevance, and comprehensiveness of each item and scale.

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 (Ebola) | UK (mpox) | Bangladesh (Nipah)* | Total* |
|---|------------------------|------------------------|------------------------|-------------------------|
| Age | | | | |
| Median (IQR; range), N | 32 (27–40; 18–76), 302 | 32 (26–40; 18–78), 406 | 36 (30–43; 18–78), 298 | 33 (27–41; 18–78), 1006 |
| Gender | | | | |
| Woman | 159/302 (52.6%) | 69/406 (17.0%) | 146/296 (49.3%) | 374/1004 (37.3%) |
| Man | 143/302 (47.4%) | 288/406 (70.9%) | 150/296 (50.7%) | 581/1004 (57.9%) |
| Other† | 0/302 | 49/406 (12.1%) | 0/296 | 49/1004 (4.9%) |
| Nature of residence | | | | |
| Urban | 130/302 (43.0%) | 264/406 (65.0%) | 103/300 (34.3%) | 497/1008 (49.3%) |
| Rural | 172/302 (57.0%) | 142/406 (35.0%) | 197/300 (65.7%) | 511/1008 (50.7%) |
| Proximity to illness‡ | | | | |
| Personal lived experience of illness | 51/302 (16.9%) | 13/406 (3.2%) | 30/300 (10.0%) | 94/1008 (9.3%) |
| Close relationship with someone who had illness | 208/302 (68.9%) | 37/406 (9.1%) | 81/300 (27.0%) | 326/1004 (32.5%) |
| Health-care worker | 49/302 (16.2%) | 112/406 (27.6%) | 60/300 (20.0%) | 221/1008 (21.9%) |
| Outbreak support staff | 61/302 (20.2%) | 18/406 (4.4%) | 30/300 (10.0%) | 109/1008 (10.8%) |
| Other community member | 55/302 (18.2%) | 262/406 (64.5%) | 115/300 (38.3%) | 494/1008 (49.0%) |
| Self-reported understanding of disease | | | | |
| Heard of it but does not know details | 39/302 (12.9%) | 162/406 (39.9%) | 162/299 (54.2%) | 363/1007 (36.0%) |
| Know basic details | 152/302 (50.3%) | 212/406 (52.2%) | 111/299 (37.1%) | 475/1007 (47.2%) |
| Know more than the basics | 111/302 (36.8%) | 32/406 (7.9%) | 26/299 (8.7%) | 169/1007 (16.8%) |

Data are n/N (%), unless stated otherwise. Demographic and contextual characteristics of respondents who participated in the validation of the RAPID Stigma Scales across the three study sites. *Denominators vary with completeness of the data. †The UK cohort included 43 respondents who were non-binary and two respondents who preferred not to say. ‡Respondents might be included in more than one category.

Table 1: Characteristics of respondents who completed the RAPID Stigma Scales across the three study cohorts

Uganda National Council for Science and Technology (SS2727ES), and the International Centre for Diarrheal Disease Research, Bangladesh research and ethical review committees (PR-23128). No personal data were collected, and respondents provided informed consent before starting the survey. The details of relevant local psychosocial support networks were provided to respondents. The expert feedback (Delphi) process was deemed exempt from formal ethical approval following consultation with the University of Oxford's Medical Sciences Division ethics committee, as contributors were engaged as co-developers rather than as study participants.

Patient and public involvement and engagement

Two community co-investigators—one with lived experience of mpox and one with lived experience of Ebola disease—were actively involved from the study's conceptualisation to dissemination of results. Recovered patients and members of the public from the affected communities were also included as interviewees in the stakeholder interviews and expert panellists in the Delphi process. Cognitive interviews conducted with patients who had recovered and public from the affected communities also helped to direct and refine the scales. Across all sites, study plans were discussed with key community members and leaders to ensure transparency and appropriateness before initiating recruitment and data collection.

Results

1038 respondents started the survey across the three sites. After excluding ineligible respondents ($n=2$), incomplete surveys ($n=12$), and online surveys with failed attention checks ($n=16$), 1008 eligible respondents completed the draft scale items. At the interviewer-administered sites, three potential respondents declined to participate due to time constraints. Respondent characteristics are detailed in table 1.

24 draft scale items were field-tested (appendix pp 9–10). After iterative analysis, 12 items were retained for the RAPID Community Stigma Scale and four items retained for the RAPID Self Stigma Scale (figure 2).

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 exceeding 0.8 with an item that was more broadly applicable (appendix p 10). All other items had acceptable response distributions.

The correlation matrix revealed conceptually distinct clusters among the community stigma items, whereas self stigma items displayed broader correlations (appendix p 14). This pattern aligned with the conceptualisation of self stigma as a distinct construct stemming from community stigma, rather than as a subdomain within it. Consequently, we analysed the community stigma and self stigma items separately.

| Item No. | Item: People who have [X disease] are... | 3=Yes | 2=Probably | 1=Unlikely | 0=No |
|--|--|--------------------------|--------------------------|--------------------------|--------------------------|
| RAPID Community Stigma Scale | | | | | |
| <i>Initial social stigma</i> | | | | | |
| C1 | Looked down on | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C2 | Gossiped about | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C3 | Treated unkindly by the public (including online/on social media) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Provider/authority-related stigma</i> | | | | | |
| C4 | Negatively judged by healthcare workers | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C5 | Portrayed negatively in the media | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C6 | Spoken about negatively by politicians | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Structural stigma</i> | | | | | |
| C7 | Denied certain rights | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C8 | At risk of losing work or education opportunities | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C9 | Not welcome in certain places after recovery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Enduring social stigma</i> | | | | | |
| C10 | Likely to have more difficulty finding a partner after recovery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C11 | At risk of losing customers after recovery if they have a business | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C12 | Rejected by their community | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| RAPID Self Stigma Scale | | | | | |
| S1 | Going to try to keep the diagnosis a secret | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| S2 | Ashamed of the diagnosis | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| S3 | Hesitant to seek medical care for their illness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| S4 | Likely to believe they deserved the illness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Figure 2: Final RAPID Community and Self Stigma Scale structure, items, and response options

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."

A significant Bartlett's test of sphericity and a KMO of more than 0.8 for both the community and self stigma EFA datasets confirmed their suitability for EFA (appendix p 15). Guided by the preliminary factor number analyses, EFA yielded a stable and interpretable four-factor, 12-item model for community stigma after five iterations and four-item self stigma model after two iterations (appendix pp 15–17).

CFA and model comparison analyses supported a second-order model for community stigma (CFI [scaled]

0.99; RMSEA 0.04 [90% CI 0.02–0.05]; SRMR 0.04) and unidimensional model for the self stigma model (1.00; <0.01 [0.00–0.08]; 0.01), which was consistent with the a priori conceptual framework (appendix pp 18–19). The fit indices remained acceptable when examined separately for the three sites (appendix p 20). Both scales showed good internal structural validity (table 2). Item-level statistics for each study cohort are provided in the appendix (pp 21–22).

Residual correlations were generally small in both models, with two exceeding 0.10, but remaining below 0.15 in the community stigma model, and none exceeding 0.10 in the self stigma model (appendix p 23). All modification indices 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 still met key strong fit thresholds (CFI >0.95; RMSEA <0.05), and all factor loadings remained above 0.5, suggesting that the non-random sampling had minimal effect on the scale validity findings (appendix pp 11–12). In terms of reliability, both scales showed good internal consistency (ordinal alpha 0.79–0.90 for community stigma subscales; 0.83 for self stigma; table 3). Additional reliability metrics are presented in the appendix (p 24).

Multiple regression supported the hypothesised relationships with behavioural outcomes, providing evidence of external construct validity. High scores on both scales predicted higher 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 people ($\beta=-0.22$, $p<0.001$) and higher self stigma ($\beta=0.72$, $p<0.001$; table 3; appendix pp 25–30).

Discussion

This study introduces the RAPID Community and Self Stigma Scales, a set of tools developed and validated to identify stigma and support its reduction during new and re-emerging infectious disease outbreaks. In contrast to existing outbreak stigma measures, which are tailored to specific diseases or cultural settings, the RAPID scales are explicitly designed to be transferable across a range of outbreak contexts. The transferable nature of the scales is an important advancement because the initial phases of an outbreak are when stigma is often overlooked in the urgency of outbreak containment. However, this phase is also when stigma tends to be most severe and harmful due to heightened isolation and fear,^{34,35} exacerbating psychological distress and discouraging care-seeking. By identifying stigma early, the RAPID scales can help to mitigate these effects by enabling timely and appropriate interventions. The scales could also be valuable in the later phases of an outbreak to evaluate the effectiveness of stigma reduction programmes or policies.

Cross-outbreak tool design offers several practical advantages. Infectious disease outbreaks often occur unexpectedly and are typically short-lived, despite their notable effect. As a result, stigma tools developed during an outbreak are usually too late to inform timely interventions or have poor validity when created hastily.^{2,9} By contrast, reusing tools across outbreaks provides an opportunity for ongoing validation.

Moreover, outbreak response teams face finite resources and competing priorities, making it challenging to develop new tools during a crisis.² The approach used to develop the RAPID scales mirrors other areas of pandemic preparedness, such as vaccine development for “disease X”.³⁶ This approach allows work to be carried out ahead of outbreaks to facilitate fast, evidence-based interventions when they occur.³⁷

| | Mean (SD); median (range) | Standardised factor loading estimates (95% CI)* | R ² † | r-CVI‡ |
|---|---------------------------|---|------------------|--------|
| RAPID Community Stigma Scale | | | | |
| F1: Initial social stigma | 1.85 (0.86); 2 (0–3) | 0.80 (0.74–0.85) | 0.63 | 0.98 |
| C1: looked down on | 1.79 (1.11); 2 (0–3) | 0.76 (0.70–0.82) | 0.58 | 1.00 |
| 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 | 0.96 (0.84); 1 (0–3) | 0.69 (0.64–0.75) | 0.48 | 0.90 |
| 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 | 1.36 (0.92); 1–33 (0–3) | 0.89 (0.85–0.94) | 0.80 | 0.96 |
| 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 | 1.42 (0.97); 1–67 (0–3) | 0.89 (0.86–0.93) | 0.80 | 0.93 |
| 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); 1.5 (0–3) | NA | 0.56 | 0.98 |

Data reflect responses on a 4-point Likert scale, with 3 indicating yes, 2 probably, 1 unlikely, and 0 no. r-CVI=relevance content validity index. NA=not applicable. *Based on confirmatory factor analysis. †Indicate variance explained. ‡Reflects expert ratings from the final panel of 34 experts.

Table 2: Item-level descriptive statistics and validity indicators for the final Rapid Community and Self Stigma Scales

The RAPID scales were found to have robust psychometric properties, including strong content and construct validity, internal consistency, and predictive validity, in three geographically and culturally diverse contexts: mpox in the UK, Ebola disease in Uganda, and Nipah virus disease in Bangladesh. This cross-contextual applicability is an improvement on existing stigma scales, which have not been validated across more than two outbreak contexts.⁹ The scales are validated and available for use in English, Bengali, and Luganda.

The findings provide supporting evidence of predictive relationships between stigma and key public health outcomes, such as hesitancy to report symptoms, delays in seeking medical attention, and reduced acceptance of recovered individuals, which have been seen in other studies.^{5,38,39} These results reinforce the utility of the RAPID scales as tools, not only for measuring stigma, but also for predicting its effect on outbreak control. The scales' strong performance across diverse settings supports their cross-contextual applicability and reinforces observations about the shared nature of many stigma manifestations across different diseases.^{17,27}

The study has some limitations. In the UK, data were collected after the local outbreak's peak, between April 3 and Aug 27, 2024, and in Uganda, more than a year after the outbreak, potentially introducing recall bias. The sampling method ensured the representation of key subpopulations and addressed logistical constraints, facilitating validation with a heterogeneous group of respondents.^{23,29} However, the non-randomised and non-proportional design restricts the generalisability of the findings. Additionally, test-retest reliability was not assessed. In the UK, where retesting was most logistically feasible due to online data collection, it was prevented by the emergence of the clade I mpox outbreak and shifting media narratives, which introduced uncertainties about the stability of findings.

The final scales also have limitations. The Self Stigma Scale's near-perfect fit indices might be partly due to the model's simplicity (a single-factor structure with four items and two degrees of freedom). However, the scale's strong theoretical grounding, high factor loadings, satisfactory reliability, and consistent performance across diverse contexts support its validity. Similarly, the brevity of the Community Stigma subscales (three items each) minimises survey length, which is important for end-users but might limit their comprehensiveness. Three-item scales have performed well in similar health domains, providing a precedent for the shorter subscales.⁴⁰ The indirect framing of scale items expands the potential use cases for the scale and reduces the sensitivity of the questions.⁴¹ However, the scale primarily captures perceived stigma at the community level rather than individual experiences. This community-level focus limits the scales' ability to assess personal stigmatisation.

Lastly, the focus on transferability means the scales might not fully capture context-specific manifestations of

| | Criteria for acceptability | Community Stigma Scale | Self Stigma Scale |
|--|---|---|---|
| Content validity | | | |
| Face validity* | >0.80 | 0.97 | 1.00 |
| Relevance (r-CVI) | >0.80 | 0.94 | 0.98 |
| Comprehensiveness (c-CVI) | >0.80 | 0.97 | 1.00 |
| Clarity content validity | Adequate: assessed qualitatively through cognitive interviews | Adequate: assessed qualitatively through cognitive interviews | Adequate: assessed qualitatively through cognitive interviews |
| Internal construct validity | | | |
| Model fit (CFI scaled) | >0.95 | 0.99 | 1.00 |
| RMSEA (90% CI) | <0.06 (0.00 to 1.00) | 0.04 (0.02 to 0.05) | <0.01 (0.00 to 0.08) |
| SRMR | <0.08 | 0.04 | 0.01 |
| Average variance extracted | >0.50 | 0.68 (0.56, 0.63, 0.71, 0.75)† | 0.56 |
| External construct validity | | | |
| Multiple linear regression measuring symptom-reporting hesitancy | >0; p<0.05 | 0.21 (0.15 to 0.27); p<0.001‡ | 0.19 (0.13 to 0.24); p<0.001‡ |
| Multiple logistic regression measuring care-seeking hesitancy | >0; p<0.05 | 1.63 (1.22 to 2.19); p<0.001§ | 1.71 (1.33 to 2.21); p<0.001§ |
| Multiple linear regression measuring social acceptance of recovered people | <0; p<0.05 | -0.22 (-0.32 to -0.12); p<0.001‡ | NA |
| Multiple linear regression measuring self stigma | >0; p<0.05 | 0.72 (0.66 to 0.77); p<0.001‡ | NA |
| Reliability | | | |
| Internal consistency (ordinal alpha) | 0.70 to 0.95 | 0.92 (0.79, 0.83, 0.88, 0.90)† | 0.83 |

r-CVI=relevance content validity index (average). c-CVI=comprehensiveness content validity index (average). CFI=comparative fit index. NA=not applicable. RMSEA=root mean square error of approximation. SRMR=standardised root mean square residual. *Face validity score is the proportion of respondents who scored the statement "On face value, these items seem like a valid measure of external community stigma/self stigma" a 3 (mostly agree) or 4 (strongly agree) on a 4-point Likert scale. †F1, F2, F3, F4, where F1 is initial stigma subscale, F2 is provider or authority-related stigma subscale, F3 is structural stigma subscale, and F4 is enduring stigma subscale. ‡β coefficient (95% CI); p value. §Odds ratio (95% CI); p value.

Table 3: Psychometric properties of the final RAPID Community and Self Stigma Scales

stigma. For instance, they do not address associative stigma, such as stigma directed at social identities perceived to be linked to the illness, which can be highly outbreak-specific (eg, stigma towards people of east Asian appearance linked to COVID-19 or people identifying as LGBTQ+ linked to mpox).¹ Additional questions or adaptations should be used to address associative stigma when relevant.

Nonetheless, the RAPID scales, as practical, deployable tools, are a needed advancement in outbreak stigma assessment. They can be integrated into response frameworks and administered as part of rapid needs assessments to identify predominant sources, and populations experiencing heightened stigma. This integration allows response teams to tailor communication strategies, psychosocial support services, and policy interventions accordingly. Health agencies, community organisations, and researchers can also use the scales to monitor stigma dynamics in real time, guiding targeted interventions such as

Search strategy and selection criteria

The scale development process began with a systematic review of existing stigma scales used during infectious disease outbreaks, and the results were published separately by Paterson and colleagues in 2024. Six databases were used for the systematic review (MEDLINE, PsycINFO, CABI Global Health, Embase, Web of Science, and Cochrane Library) with search terms related to “stigma”, “infectious disease outbreaks”, and “scale”. There were no language restrictions, and the search covered publications from database inception until Jan 31, 2023. Eligible studies focused on acute outbreak diseases and scales needed, at minimum, evidence of face validity. The results of the systematic review were used to inform subsequent stages of Phase 1 scale development outlined in this Review.

community engagement initiatives, and training for health-care workers to mitigate discriminatory practices.

The scales’ brevity ensures feasibility in time-pressured settings and allows for incorporation into broader tools such as knowledge, attitudes, and behaviour surveys. In acute outbreak settings, where rapid decision making is essential, the scales can help prioritise stigma-related concerns alongside clinical and logistical response efforts. By providing actionable insights into stigma trends, public health authorities can incorporate stigma mitigation into their response strategies, potentially reducing care-seeking delays, and enhancing trust in response efforts.

To facilitate straightforward interpretation, mean and median scores (0–3) are used for factor and scale totals to align with the original 4-point Likert scale (no, unlikely, probably, or yes). A key consideration in applying the RAPID scales is determining the threshold at which stigma warrants intervention. This decision should be guided by an understanding of trends and implications rather than fixed cutoffs. For example, even low levels of perceived provider or authority-related stigma warrant action due to potential effect on health-care access. Additionally, a sharp increase in scores might signal the need for urgent intervention, such as community dialogues, or policy adjustments to counteract emerging stigma-related harms.

In future applications, the selection of a sampling frame could be guided by the available population affected, given that the scales have been validated with a heterogeneous sample of affected community members. When the scales are used with recovered individuals, it is recommended that psychosocial support or referral mechanisms be in place to mitigate potential distress. Before implementation in new contexts, end-users should review the items and, if necessary, pilot adaptations to ensure contextual relevance.

Future research could 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 would show the scales’ utility in evaluating stigma-reduction interventions, further strengthening their application in public health responses. Although heterogeneous sampling that encompasses the full spectrum of potential respondents is recommended during scale development, subanalyses could offer valuable insights into the extent of stigma in specific contexts, and its predictors and effects.

A useful complement to this tool would be the development of stigma-reduction guidelines tailored to different forms of stigma across various levels of outbreak response actors, ensuring that findings from the scale can directly inform targeted interventions. Lastly, although indirect responses can still reflect individual experiences of stigma and make the questions less sensitive,⁴¹ the scale could be adapted to capture personal stigma experiences directly.

In conclusion, the RAPID Community and Self Stigma Scales are the first validated and adaptable tools intentionally designed for assessing stigma across diverse outbreak contexts. By addressing a gap in stigma assessment, these scales offer researchers, practitioners, and policy makers a means to rapidly assess and mitigate stigma during infectious disease outbreaks. The integration of such tools into outbreak response frameworks has the potential to enhance public health outcomes, reduce the social and psychological burden of stigma, and foster effective and equitable outbreak responses globally.

Contributors

AP, AC, OK, TS, KHD, HT, BJ, JS, NG, PO, and AR were involved in conceptualisation of the study. OK, KHD, AP, AC, YS, and NK-M were involved in survey development and data collection in Uganda. TS, DIR, MSIK, KIAC, WRA, and SMS were involved in survey development and data collection in Bangladesh. HT, WN, and CO were involved in survey development and recruitment in the UK. AP, KKM, AC, PO, and AR had access to all the datasets and verified the underlying data. AP and KKM conducted all analyses. OK, TS, KHD, HT, FNA, SSA, EAM, LGB, HB, PC-D, JD, ERG, MZH, MBH, EJ, SKM, GAM, SN, WN, CO, DIR, KR, SR, SS, HLS, MTS, ALS, YS, ES, RKJT, STa, TST, STo, and XW contributed as expert Delphi panellists. AP wrote the first draft of the manuscript with review from all authors. All authors approved the final manuscript.

Declaration of interests

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