

## DEVELOPMENT OF THE MALAY VERSION OF THE ENGLISH HIV STIGMA QUESTIONNAIRE: A REVIEW

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### ABSTRACT

**Background:** HIV Stigma impeded the screening, treatment and compliance of HIV/AIDS management. Therefore, the data on the burden of HIV stigma is vital. This study aims to examine the cross-cultural translation adaption of the Malay version of HIV Stigma Questionnaires and also examine its validity and reliability.

**Materials and Methods:** The standard English version of the HIV Stigma Questionnaire by The Global Stigma and Discrimination Indicator Working Group (GSDIWG) and STRIVE research consortium was undergone a Malay translation via forward-backward methods. Content validity by the expert committees and reliability by preliminary pilot testing was done.

**Results:** The content validity was approved by the expert committees with acceptable reliability during the preliminary survey analysis. Internal consistency was acceptable with Cronbach's alpha value was 0.76.

**Conclusion:** The validation of the Malay version of HIV Stigma questionnaire reveals an excellent cross-cultural adaption, content validation and reliability. This Malay version is open for potential Malaysia's HIV Stigma studies in the future in parallel with our national strategic planning on HIV to end HIV by 2030.

**Keywords:** *HIV Stigma, validation, questionnaire*

## 1.0 Introduction

HIV stigma is a set of negative attitudes and beliefs about people living with HIV (PLHIV). It is often related to the context of being prejudice and labelling PLHIV as part of a group that is believed to be socially unacceptable. HIV stigma also imposes threats with regard to the physical well-being and mental health of PLHIV. For instance, if their HIV status is known, they believe that they might be discriminated against or judged negatively.

The issues of social judgement and discrimination itself have contributed to a negative impact towards the screening program, treatment and compliance of HIV/AIDS management. Therefore, eliminating or somewhat reducing HIV Stigma is a potent strategy in eliminating HIV/AIDS infections. This strategic planning should embark on the evidence-based decision making where the data on the burden of HIV stigma is vital.

According to the Global AIDS Monitoring Report 2019, 87,041 PLHIV were identified in Malaysia until December 2018. Approximately 90% were men and the rest were females. From these statistics, more than 70% of the HIV new infections were reported among people aged 20 to 39 years old in 2018. In the general population, the incidence of people newly infected with HIV in 2018 per 1,000 uninfected population (15-49 years) was 0.18. Among key populations, the percentage of MSM (men having sex with men) living with HIV was the highest - 21.6% in 2017, followed by PWID (people who inject drugs) - 13.5%, transgender women – 10.9% and female sex workers – 6.3%. The rate of sexually-transmitted HIV infection is swiftly increasing, representing a shift in the mode of transmission from drug use to sexual behaviours [1].

To date, a wide range of research has been conducted to conceptualize HIV stigma, explore its forms, contexts and consequences and understand individual and community responses. This research has yielded a wide range of survey questions and scales for measuring stigma in various cultural contexts and with different populations, including people living with HIV and the general population. But the Malays language's standard questionnaire for HIV Stigma in Malaysia has still unseen.

The Global Stigma and Discrimination Indicator Working Group (GSDIWG) and STRIVE research consortium has established HIV Stigma questionnaire consists of six domain which was identified based on previous research and systematic reviews [2]. This questionnaire should be the ultimate standard for collecting HIV Stigma index among general population to ensure standard tools for international comparison. The key conceptual domains in the 6-item questionnaires include:

- i. **Anticipated stigma** (the fear of negative ramifications should one's HIV status become known, should one associate with a person living with HIV or should one test positive for HIV)
- ii. **Perceived stigma** (community members' perception of stigma that is directed toward people living with HIV by community members)

- iii. **Fear of HIV infection** (fear of infection through casual contacts with PLHIV)
- iv. **Social judgement** (shame, blame, prejudice and stereotypes)
- v. **Experienced stigma** (the experience of discrimination, based on HIV status or association with a person living with HIV or other stigmatised group, that falls outside the purview of the law)
- vi. **Discrimination** (the experience of discrimination that falls within the purview of the law)

This study aims to examine the cross-cultural translation adaption of the Malay version of HIV Stigma Questionnaires and also examine its validity and reliability. The final version of the questionnaire from this preliminary pilot test will be embarked on National Health Survey involving larger sample size.

## 2.0 Materials and Methods

The translation and validation process for this involved several steps started with forward-backward translation, subsequently content validity, preliminary pilot testing and reliability analysis [3,4] (See Figure 1).

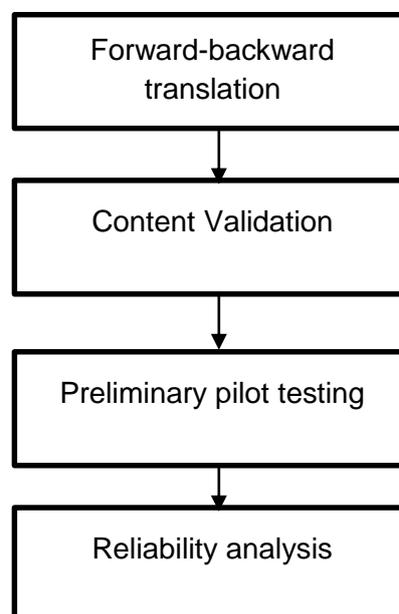


Figure 1: Stage of Cross-cultural and Content Validation of Malay Version of HIV Stigma Questionnaire

### **2.1 Forward-backward translation**

The initial translation from the original English version of HIV Stigma Questionnaires to the Malay language had been done by three independent translators [3]. All three translators are bilingual (English and Malay language) with 2 of them are Malay language's mother tongue. This should affirm better nuances of the target language [4]. The first translator was a researcher who is aware of the concepts the questionnaire intends to measure. This should provide a translation that is more closely resembles the original instrument. The other two translators who were categorized as a naive translator, who were unaware of the objective of the questionnaire, produce the second translation so that subtle differences in the original questionnaire may be detected [4]. Discrepancies between the three translators was analysed and discussed.

The initial translation (forward translation) should be independently back-translated (translate back from the Malay language into the English) to ensure the accuracy of the translation. Misunderstandings or unclear wording in the initial translation may be revealed in the back-translation [4]. As with the forward translation, the backward translation was performed by all three same translators [4]. Two of them were unaware of the intended concepts of the questionnaire (naïve translators). This method should avoid bias as the backward translators should preferably not be aware of the measures [3,4]. Again, all the discrepancies between the three translators was analysed and discussed until a consensus to synthesize of the final version of the Malay language established.

### **2.2 Content validation**

A group of expert committees subsequently formed to review the translated version of the questionnaire [3,4]. Members of the committee include experts in HIV Programme managers in the Ministry of Health, Public Health Specialist, infectious diseases physician and researchers. They are familiar with the construct of interest. The group also include a methodologist, both the forward and backward translators. The expert committee review all versions of the translations and determine whether the translated and original versions achieve semantic, idiomatic, experiential, and conceptual equivalence [3,4]. Any discrepancies will need to be resolved, and members of the expert committee will need to reach a consensus on all items to produce a pre-final version of the translated Malay version of HIV Stigma questionnaire.

### **2.3 Preliminary pilot testing**

As with developing a new questionnaire, the prefinal version of the translated Malay version of HIV Stigma questionnaire has been pilot tested on a small sample of 36 respondent from a various socio-economic background [5]. After complete answering the translated questionnaire, the respondent is asked (verbally by an interviewer or via an open-ended question) to elaborate what they thought of each questionnaire item and their corresponding response meant. This approach allows the investigator to make sure that the translated items retained the same meaning as the original items, and to ensure there is no confusion regarding the translated questionnaire. This process may be repeated a few times to finalize the final translated version of the questionnaire (see Table 1).

**Table 1: Translation of HIV stigma questionnaire from English to Malay language**

No	Soalan/Questions	Ya/Yes	Tidak/No
1	Adakah anda takut bahawa anda boleh dijangkiti HIV jika terkena air liur seseorang yang menghidap HIV? <i>Do you fear that you could contact HIV if you come into contact with the saliva of a person living with HIV?</i>		
2	Adakah anda bersetuju dengan pertanyaan berikut? “Saya akan berasa malu jika ahli keluarga saya menghidap HIV.” <i>Do you agree with the following statement? “I would be ashamed if someone in my family had HIV.”</i>		
3	Pada pendapat anda, adakah seseorang berasa ragu-ragu untuk membuat ujian HIV kerana takut akan reaksi masyarakat jika keputusan ujian adalah positif HIV? <i>In your opinion, are people hesitant to take an HIV test due to fear of people’s reaction if the test result is positive for HIV?</i>		
4	Adakah orang yang menghidap atau disyaki menghidap HIV akan hilang rasa hormat atau kedudukan? <i>Do people living with or thought be living with HIV lose respect or standing?</i>		
5	Adakah anda akan membeli sayur-sayuran segar dari pekedai atau pembekal tersebut jika anda mengetahui bahawa dia menghidap HIV? <i>Would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person had HIV?</i>		
6	Adakah anda berpendapat bahawa kanak-kanak penghidap HIV sepatutnya boleh bersekolah Bersama dengan kanak-kanak yang bukan penghidap HIV? <i>Do you think children living with HIV should be able to attend school with children who are HIV negative?</i>		

### 2.4 Reliability analysis

Data were catalogue and probe into SPSS version 24.0 software for reliability analysis via internal consistency. The criteria for acceptable range for Cronbach alpha is set at at least 0.7 [6].

### 3.0 Result

A total of 36 respondents participated in this preliminary pilot testing. The socio-demographic characteristics of respondents was tabled in Table 2. The table shows diversity of respondents in terms of age category, gender, ethnicity and education levels.

The result of the preliminary survey was also analysed via descriptive statistics. The percentage of stigma in each domain was determine by percentage of respondents who answered “Yes” in each six question. The result showed that anticipated stigma was the highest reported stigma domain, followed by perceived stigma and social judgement. The lowest stigma domains were

discrimination, experienced stigma and fear of infection (See Table 3). Finally, the reliability test was done via internal consistency as indicator. The Cronbach alpha for this preliminary pilot test was 0.76 (See Table 4).

**Table 2: Sociodemographic characteristics of respondents (n=36)**

Variables	n	%
<b>Age category</b>		
13-30	12	33.3
30-50	14	38.9
>50	10	27.8
<b>Gender</b>		
Male	16	44.4
Female	20	55.6
<b>Ethnicity</b>		
Malay	16	44.4
Chinese	6	16.7
Indian	2	5.6
Bumiputera@others	12	33.3
<b>Education</b>		
Primary	2	5.6
Secondary	14	38.9
Tertiary	20	55.6

**Table 3: Stigma percentage based on each domain**

Domain	Question	Yes	No
<b>Fear of infection</b>	Do you fear that you could contact HIV if you come into contact with the saliva of a person living with HIV?	41.7%	58.3%
<b>Social Judgement</b>	Do you agree with the following statement: "I would be ashamed if someone in my family had HIV."	52.8%	47.2%
<b>Anticipated stigma</b>	In your opinion, are people hesitant to take an HIV test due to fear of people's reaction if the test result is positive for HIV?	75.0%	25.0%
<b>Perceived Stigma</b>	Do people living with or thought be living with HIV lose respect or standing?	72.2%	27.8%
<b>Experience Stigma</b>	Would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person had HIV?	33.3%	66.7%
<b>Discrimination</b>	Do you think children living with HIV should be able to attend school with children who are HIV negative?	30.6%	69.4%

**Table 4: Reliability test and its description**

Reliability test	Result	Interpretation*
<b>Cronbach alpha</b>	0.76	Acceptable

## 4.0 Discussion

A valid scale is needed to measure HIV/AIDS stigma quantitatively in order to provide a mean to inform and to plan and evaluate the interventions. The research on HIV/AIDS stigma to date had suggested a number of negative psychological, interpersonal and social consequences. HIV stigma can be classified as enacted or felt [7]. Enacted stigma means individually or collectively applied sanctions such as discrimination or prejudice. Felt stigma refers to the feelings of shame, guilt and fear.

According to Health Stigma Framework [8], there are three stigma mechanisms through which PLHIV experience and respond to social stigma: (i) experienced stigma, (ii) anticipated stigma, and (iii) internalized stigma. Experienced stigma represents past experiences of discrimination or prejudice by others. Anticipated stigma refers to the expectation of repercussions in the future. Internalized stigma is related to the acceptance of negative social perceptions.

In this study, using the Malay version of HIV Stigma questionnaires, we examined both types of stigma – enacted and felt, as well as all three mechanisms of stigma – experienced, anticipated and internalized.

This study is the first validation study for the Malay version of HIV Stigma questionnaires. The overall findings show that the Malay version of HIV Stigma questionnaire was culturally accepted and the content validity and reliability was excellent. The questionnaire has undergone systematic forward-backward translation process. The subsequent review by the expert committee affirms the excellent content validity of the Malay version questionnaire. Finally, the reliability test of the pilot testing should give good trajectory of the reliability of data during the full study later on as it was categorized as acceptable [9]. Hence, the Malay version questionnaire will be embarked on larger scale of national health survey in future.

This study was also taking advantage of the validation process for the two indicators for HIV Stigma by UNAIDS which was the question no. 5 and 6 in this questionnaire. This validated questionnaire should provide researchers and policymakers with a valid set of data in identifying the burden of HIV Stigma in Malaysia. It also warrants for subsequent intervention especially in addressing the type of negative attitudes in a local setting in the veins of Malaysia's national strategic plan for ending HIV by 2030 [10]. Therefore, we are encouraging researchers and policymakers to continue exploring the area of HIV Stigma and collecting more data as evidence-based decision making.

## 5.0 Conclusion and recommendation

The validation of the Malay version of HIV Stigma questionnaire reveals an excellent cross-cultural adaption, content validation and reliability. This open for potential Malaysia's HIV Stigma study in the future in parallel with our national strategic planning on HIV to end HIV by 2030.

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This study was registered under the National Medical Research Registry (NMRR), Ministry of Health Malaysia (Registration number NMRR-19-867-47973) and obtained ethical approval from Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia.

## Declaration

We declare no competing interests.

## Authors contribution

All authors contribute to the conceptualization and data collection of the manuscript. MSAK, NAM, MHT, AS, AA contribute to writing of this manuscript. All authors reviewed the final manuscript and approved the final version for publication.

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