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# Development and validation of a self-management questionnaire for people living with HIV in low- and middle-income countries (HIV-SM LMIC tool)

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## Abstract

**Purpose** The main objective of this research is to develop and validate a comprehensive self-management tool for PLWH (HIV-SM LMIC tool) in Ethiopia.

**Method** Item development followed a recommended procedure. Item concepts were based on two previously published articles by the same authors, guided by the Individual Family Self-management (IFSMT) theoretical framework. The developed items were translated from English into Amharic (a local language in Ethiopia). Two rounds of face and content validation were conducted with HIV program experts, academics, people outside the health sector, and HIV patients. A total of 61 participants (52 in the first round and 9 in the second round) participated in the validation process. All participants evaluated the content and face validity of each item and provided qualitative judgments, comments, and suggestions.

**Results** In the first round of validation, most participants were health professionals (53.8%), followed by HIV patients (19.2%) and HIV program experts/researchers (9.6%). Nine participants took part in the second round. Initially, 117 draft items were refined into 63 for validation. I-FVI (individual face validity index) values ranged from 0.56 to 0.98, with 43 items (68%) scoring  $\geq 0.80$ , indicating high face validity. I-CVI (individual content validity index) values ranged from 0.76 to 1.00, with 61 items (97%) scoring  $\geq 0.80$ , demonstrating high content validity. Common qualitative feedback highlighted translation and contextualization issues in the Amharic version and overlapping concepts. Based on FVI, CVI, and qualitative feedback, particularly patient comments, 26 items were dropped or merged, resulting in a 37-item tool. In the second round, 31 items scored above 0.80 on the CVI. Three items were removed due to low CVI ( $< 0.70$ ) and redundancy, while two were dropped based on participant feedback. The remaining 32 items had kappa values  $> 0.74$ , indicating excellent relevance. Both English and Amharic versions were revised.

**Conclusion** A comprehensive 32-item HIV-SM LMIC tool tailored to HIV patients in low- and middle-income countries was developed following a rigorous psychometric evaluation process. Further research on its construct validity, criterion validity and reliability are recommended before its use. In addition, future studies should assess the cross-cultural validity of the final instrument.

**Keywords** Self-management, HIV patients treatment outcome, Low and middle income countries, HIV-SM LMIC questionnaire

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## Introduction

HIV (human immunodeficiency virus) has taken the lives of an estimated 40.4 million people worldwide since the beginning of the epidemic and it is now claiming two million lives a year [1, 2]. Currently, about 39.0 million people globally are living with HIV, of which 25.6 million are in Africa [1]. Although the overall prevalence in Ethiopia has been declining over the past few decades, the current prevalence among women is higher than in the past [3]. The impact of HIV goes beyond the numbers that indicate the magnitude. HIV affects household welfare, it causes loss of productive population and it is highly associated with poverty [4, 5]. Moreover, HIV affects the socio-cultural cohesion of the patient because of its associated stigma and a single problem among people living with HIV (PLWH) can create multiple cascades of problems, e.g. stigma leads to non-disclosure, which in turn leads to increased HIV transmission [6–8].

Management of HIV requires long-term commitment from the patient, the community, and the health system, which increases the burden on the family and the health system [9, 10]. In the past few decades, significant strides have been made in controlling the HIV epidemic and improving care and support for HIV patients. However, various challenges persist such as inadequate case management, non-adherence of patients to medication, insufficient self-care practices, discrimination, and social stigma, which mainly as the result of long term complacency [11, 12]. These problems frequently lead to HIV treatment failure and the development of drug resistance. Research findings indicate that a 30% non-adherence rate leads to a 9% HIV treatment failure, with even minor deviations from adherence significantly increasing the risk of HIV drug resistance [13, 14]. Addressing these challenges effectively can be achieved through the adoption of self-management practices, which involve promoting healthful behaviors, increased responsibility of the patients and empowered decision [15, 16]. This method has been recommended as a valuable practice capable of reducing the overall burden on the healthcare system and improving the quality of life for HIV patients [15, 9, 16–18]. The new WHO guideline on self-care interventions for health also affirms that self-care interventions have the potential to provide more opportunities for individuals to make informed decisions regarding their health and health care [19].

Measuring self-management practices among patients with chronic diseases is crucial for monitoring treatment outcomes, tailoring interventions specific to the context, and mitigating the negative consequences of treatment failure [20–22]. Hence, developing a reliable and valid tool to measure self-management among HIV patients in the context of developing countries is essential for

enhancing diagnosis, screening, and assessing specific patient health characteristics [23, 24]. Although several self-management assessment tools exist for evaluating self-management practices among HIV patients, many have limitations due to a lack of comprehensiveness or a focus on specific populations. For example, the tool developed by Talitha et al. [25] targets adolescents, while the tool developed by Wabel et al. [26] focuses on women in developed countries. Other tools assess self-efficacy related to specific health issues, such as the tool by Kenneth et al. [27], which evaluates perceived medical conditions, and the tool by Mallory et al. [28], which measures medication adherence.

A comprehensive self-management questionnaire is essential for optimizing patient care in low- and middle-income settings. Additionally, it provides critical support for research efforts aimed at improving HIV care and treatment. Developing such a tool would enhance understanding of the challenges faced by people living with HIV (PLWH). Therefore, the primary objective of this research is to develop and validate a comprehensive self-management tool for PLWH (HIV-SM LMIC tool) in Ethiopia.

## Methods

### Context of the study

This study is part of a series of research efforts aimed at developing a comprehensive self-management tool for people living with HIV (PLWH) in Ethiopia. Among these studies are a qualitative study that examined the importance of self-management from the perspectives of healthcare providers and experts [29] and a meta-synthesis that explored experiences and perspectives on self-management [30]. In this paper, we report on the item development phase as well as the face and content validity of the developed items, based on the findings and recommendations of the two previous studies.

### The procedures followed during development of the items

The item development process was adherent to standard procedures for developing measurements in medicine [31]. In alignment with this recommendation, results from the qualitative study and a meta-synthesis study were utilized. The qualitative study assessed the need for and importance of self-management from the provider perspective, while the meta-synthesis focused on the patient perspective [29, 30]. The Individual and Family Self-Management Theory (IFMST) model was used to structure the steps of item generation, since it is a comprehensive model that can encompass all experiences of HIV patients [32]. The IFMST model provides a structure where the construct of self-management is defined within the context of the individual, specifically the person

living with HIV, and their families. Four dimensions of self-management are defined: context, process, proximal-outcome, and distal-outcome. Items were then developed under each of these domains using a 5-point Likert scale. The research team initially generated a comprehensive draft of 117 items. First, one researcher developed the item list based on the previously mentioned framework. Then, a second research team member reviewed the entire list, leading to subsequent revisions. Through this iterative process, the list was refined and condensed to 63 items.

### Tool translation to local languages

After the initial development of the items, all items were translated into Amharic, the most widely spoken language in Ethiopia. The translation was conducted by an expert in health questionnaire translation, followed by a back-translation from Amharic to English by a second expert. A third expert then reviewed both the forward and back-translations to produce the final translated version. Throughout the validation process, both the Amharic and English versions of the tool were assessed. The integration of the Amharic version was essential for two reasons: (1) some respondents, including HIV patients who participated in the face and content validity assessment, did not understand the English version, and (2) the next phase involves piloting the tool among HIV patients, many of whom may not be proficient in English.

### Expert selection for face and content validation

Various groups of participants, and PLWH were selected from various parts of the country to evaluate the face and content validity of the items. The validation process was conducted in two phases, with participants selected in two separate rounds. Notably, some participants ( $n = 4$ ) took part in both rounds of the validation process. The

selection of participants was conducted using purposive selections based on expertise and expertise on issues related to HIV service delivery.

### Round 1

Participants included in the first round of validation comprised of individuals with a PhD in HIV-related topics, HIV program experts, academicians, and health-care providers (such as nurses, medical doctors, and health officers), and in Ethiopia. These participants were selected from four different regions in Ethiopia and had extensive national experience working in various organizations, including government health offices, universities, research institutes, health centers, and hospitals. In addition, HIV patients from the same regions from health facilities were also included (Table 1).

### Round 2

Participants included in the second round of validation consisted of individuals with a PhD in HIV-related topics, HIV program experts, academic researchers, and people outside of academia or health sector in Ethiopia. These participants were recruited from three different regions in Ethiopia and recruited from various organizations, including government health offices, universities, research institutes, and private institutions (Table 2). The reason for including people from outside the academia or health sector was to get an understanding of whether the English and Amharic versions of the items were easily understood by those people.

### Face and content validation methods

Respondents were asked to rate and comment on the clarity and relevance of each item. Items were assessed for face validity using Face Validity Index (FVI), Face Validity Ratio (FVR), and qualitative comments. For

**Table 1** Characteristics of participants involved in the first-round face and content validity

No	Study participants	Work experiences	Organization	Location
1	HIV-program experts	Currently working with HIV-projects or people who have worked for at least five years in HIV related projects	Ministry of Health, research institutes, Addis Ababa regional health bureau	Addis Ababa
2	Academic researchers	Researchers who have research experience in HIV related issues and employed at different universities	Universities in Ethiopia	Hawassa Jimma
3	Healthcare providers	Currently providing services (nurse, health officer or physician) at ART clinics at health facilities	Addisu Gebeya health center (HC) Addis Ketema HC	Addis Ababa
4	HIV patients	They are HIV patients registered at health facilities and are employed to provide support to other HIV patients in terms of adherence and counselling. These individuals are commonly referred to as adherence supporters or counsellors	Bole 17 HC Hidasse HC Mikililand HC Wereda 03 HC Melka Oda hospital Hawassa University Comprehensive Specialized Hospital (HUCSH)	Shashemene Hawassa

**Table 2** Characteristics of participants selected for second round face and content validity

No	Study participants	Working experiences	Organization	Location
1	HIV-program experts	Currently working with HIV-projects or people who have worked for at least five years in HIV related projects	Ministry of Health, research institutes, Addis Ababa regional health bureau	Addis Ababa
2	Academic researchers	Researchers who have research experience in HIV related issues and employed at different universities	Universities in Ethiopia	Hawassa Jimma
3	People outside academia or healthcare	Psychologists or accountants who work in different kinds of activities out of the health sector	Employee in private institutions	Addis Ababa

content validity, items were validated using Content Validity Index (CVI), Content Validity Ratio (CVR), and qualitative comments. FVI and CVI are indices for interrater agreement used to quantify face and content validity of a tool, respectively. FVR and CVR are interrater agreement indices that take chance agreement into account. FVI, FVR, CVI, and CVR can be assessed both at the item level (I-FVI, I-FVR, I-CVI, and I-CVR) and at the scale level (S-FVI, S-FVR, S-CVI, and S-CVR) [33]. The values of agreement on the relevance of an individual item, ranging from 0 to 1.0, while the values of I-FVR and I-CVR range from – 1.0 to 1.0.

### Sample size

There is no common method of estimating sample size for studies designed to assess face and content validity. Some authors recommend a minimum of three experts and no more than ten experts are usually used [34, 35]. Due to the complexity of the challenges faced by people living with HIV in low-income settings and to obtain a broader range of views on the face and content validity of the items, we opted for a larger and more diverse number of respondents from various areas to evaluate the items. A total of 61 participants participated in the two rounds of face and content validation, 52 in the first round and 9 in the second round.

### Data collection tool

For each item of the composed HIV-SM LMIC tool, we designed four key questions to assess the face and content validity of each item. The first question evaluates the clarity of the item using a response scale ranging from 1: not clear to 3: quite clear. Followed by an open-ended question that solicits reasons and suggestions for improvement of the item. The third question assess relevance of the item with a response scale of 1: not relevant – 2: somewhat relevant – 3: quite relevant – 4: highly relevant. The fourth question prompts respondents to provide reasons and suggestions for improvement on the relevance of the item. Respondents were requested to give special attention for cultural context, Amharic

translation, and phrasing of questions in the context of stigmatization.

### Data collection process

The data collection tool was distributed in hardcopy format, electronically via email, and also through Telegram, a messaging social media platform. HIV-program experts and academic professionals received the questionnaire electronically and submitted their responses via email. Healthcare providers and HIV patients received the questionnaire in paper form and response received in face to face. Participants were given 2–7 days to complete the questionnaire. Prior to data collection, researchers (TLD, HK) provided information about the nature of the study to participants at health facilities. For participants contacted via email or Telegram, an information sheet detailing the content and purpose of the study was provided, and clarifications were addressed via telephone calls whenever it was needed. To ensure a thorough understanding of suggestions and nuances, researchers (TLD, HK) visited all health facilities to discuss the feedback received after respondents finished scoring the items. Filled questionnaires were collected via email or Telegram from participants contacted through these platforms. Additional comments were obtained by following up with these participants via phone calls.

### Data management and analysis

Sociodemographic characteristics of respondents, quantitative scores and qualitative comments and suggestions were collected using various methods, then transferred to Excel for data management and analysis. The quantitative data in Excel format was exported to SPSS version 28 for statistical analyses. Descriptive statistical methods were employed to analyse socio-demographic characteristics of the respondents and to estimate individual and scale-level values of FVI and CVI.

The ordinal scales of clarity and relevance were dichotomized into clear (= 1) vs. not clear (= 2) and relevant (= 1) vs. not relevant (= 2). The I-FVI, I-FVR, I-CVI, and I-CVR were computed as the number of respondents reporting the item as clear or relevant divided by the total

number of respondents, while FVR and CVR were calculated using Lawshe's method [33, 36]. These values can be expressed using the following formulas:

$$I - FVI \text{ or } I - CVI = \frac{Ne}{N} \text{ and } FVR \text{ or } CVR = \frac{Ne - \frac{N}{2}}{\frac{N}{2}}$$

where Ne = the number of participants and N = the total number of participants.

Due to the fact that high number of experts or participants were included in this study, the averaging calculation method (S-CVI/Ave) was chosen to estimate the S-CVI [33, 36]. Kappa statistic was calculated to reflect the degree of agreement beyond chance. The Kappa statistic for the CVI was calculated with the formula:  $K = (I - CVI - Pc) / (1 - Pc)$ , where  $Pc = [N! / A! (N - A)!] * 0.5 N$ , and A = number of participants that agreed on with sentence "the item is relevant". The qualitative data from different participants were compiled and thematized for each item. Microsoft Excel was utilized to analyse suggestions from respondents. From the suggestions, we generated quantitative data summarizing the qualitative judgments regarding whether to delete, revise, or keep items.

#### Adaptation of the questionnaire

In the two rounds of the validation process, decisions regarding whether to keep, revise, or delete items depended on the I-CVI values and the qualitative judgments of the respondents. The I-FVI or I-FVR served as additional information helping the decision made based on the CVI and qualitative judgment. Generally, items with I-CVI values for the relevancy component greater than 0.79 are considered relevant, those equal to 0.70–0.79 needed revision, and those with less than 0.70 needed to be excluded [33, 36]. Suggestions for improvement on the items were systematically evaluated primarily based on the values of CVI and qualitative judgment. After completing the first round of the validation process, adjustments were made to the items, and then the second round of validation began with a smaller but diverse group of participants. The same process of analysis, selection, and revision of items was followed during the process of second-round face and content validation.

#### Ethical considerations

This study was approved by the Institutional Review Board (IRB) from College of Medicine and Health Sciences, Hawassa University in Ethiopia (Ref. No. IRB/337/15). Permission was granted in the health facilities before contacting the health service providers. In addition, all the participants were told about the benefits and risks of the study and informed verbal consent was obtained. Participation in this study was based on the willingness of the invited participants. Privacy and

confidentiality were ensured through various methods such as deidentification or excluding names or other identifiers.

## Results

### Socio-demographic characteristics of participants

In total, 52 participants participated in the initial round of face and content validation process of the HIV-SM LMIC tool. The mean age of participants was 39.25 years (SD 12.08), the majority (53.8%) were health professionals, followed by HIV patients (19.2%) and HIV program experts or academic researchers (9.6%). In the second round of validation, nine participants assessed the items, three of them were non-health professionals and six were experts in public health and HIV-related activities.

### Process of item generation and validation

As depicted in Fig. 1, the development and validation process of the tool comprised five stages to produce the final list of items for subsequent validation. Although 117 items were initially developed, subsequent revision by the researchers resulted in a refined 63 items for subsequent validation steps.

### Round one face and content validity

Summary of the first round of face and content validity and qualitative suggestions of participants for each item are presented in Table 3.

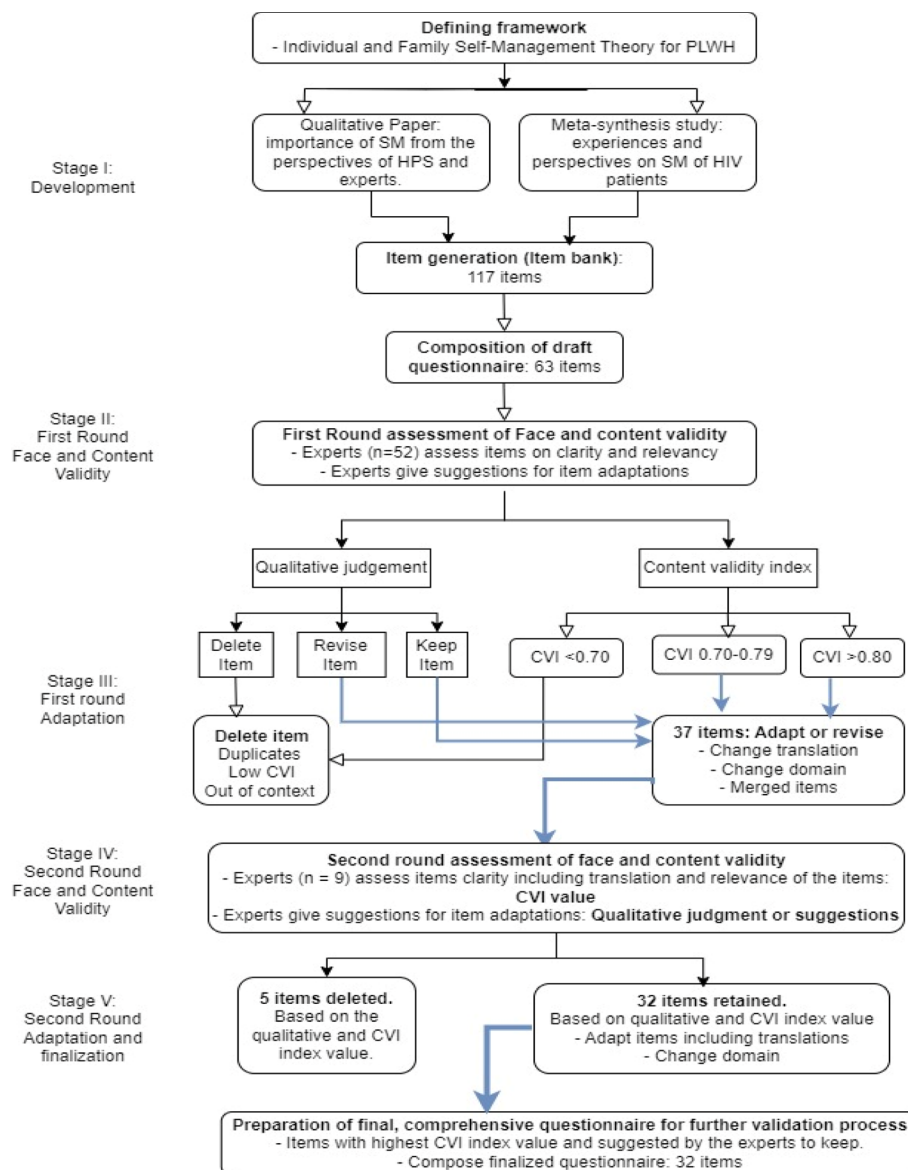
#### Face validity

As shown in Table 3 the I-FVI values ranged from 0.56 to 0.98, while I-FVR values ranged from 0.12 to 0.96. Fourteen items (22%) had an I-FVI value greater than 0.90, and twenty-nine items (46%) had an I-FVI value between 0.80 and 0.89, indicating high face validity or better clarity of 43 items (68%). Twelve items (19%) had an I-FVI value that lay between 0.70 and 0.79, and eight items (13%) had an I-FVI value of less than 0.70, necessitating revisions to these items. The S-FVI/Ave and S-FVR/Ave values were 0.82 and 0.64, respectively, indicating good level of face validity of the tool but also highlight the need for improvement in a considerable number of items (24%).

#### Content validity

As shown in Table 3 the I-CVI values ranged from 0.76 to 1.00, while the I-CVR values ranged from 0.51 to 1.00. One item achieved perfect agreement with an I-CVI and I-CVR values of 1.00, indicating unanimous consensus among respondents on its relevancy. Thirty-four items (54%) attained an I-CVI value of  $\geq 0.90$ , and the values for 27 items (43%) fell within the range of 0.80 to 0.89, indicating high content validity for 61





Note: PLWH: people living with HIV; SM: self-management; HPS: health professionals; CVI: Content validity index.

**Fig. 1** Flowchart of HIV-SM tool development and face and content validity

items (97%). The rest two items attained a value of less than 0.80. However, items related to 'perceived health status' and 'perceived future health statuses' scored between 0.70 and 0.79, necessitating revisions for those items. The S-CVI/Ave and S-CVR/Ave values were 0.90 and 0.81, respectively, indicating excellent overall content validity of the questionnaire.

#### Qualitative comments and suggestions

Almost all items received suggestions and comments from participants, with the most prevalent feedback being around translation issues in the Amharic version, particularly regarding the lack of contextualization in the selection of words or phrases. Many participants also offered suggestions for enhancing the items. Table 3

**Table 3** First round validation of HIV-SM LMIC tool and items selection

Item Code	Participants' qualitative judgment	Item clarity scores			Relevance CVI			Final decision and reasons for deleted items		
		N	Kappa <sup>2</sup>	FVI <sup>1</sup>	FVR <sup>2</sup>	N	Kappa <sup>2</sup>	CVI <sup>1</sup>	CVR <sup>3</sup>	
CCS1	Revise: make more general question specific to HIV	51	Fair	0.57	0.14	48	Excellent	0.90	0.79	Keep and revise
CCS2	Revise: include examples of side effects	52	Good	0.63	0.27	48	Excellent	0.98	0.96	Keep and revise
CCS3	Remove: OI asked in later questions	52	Fair	0.56	0.12	47	Excellent	0.87	0.74	Delete: Qualitative suggestion and expert patient CVI scores <0.80
CP1	Revise: It should focus on availability of the services	52	Excellent	0.83	0.65	46	Excellent	0.98	0.96	Keep and revise
CP2	Revise: physical access to HF	47	Good	0.64	0.28	44	Excellent	0.86	0.73	Delete: Distance is highly subjective and relative and expert CVI scores <0.80
CP8	Revise	51	Excellent	0.75	0.49	47	Excellent	0.85	0.7	Delete: low CVI score (0.38) by expert patients & item measures more of structural problems of HF
CP9	Remove	50	Good	0.66	0.32	44	Excellent	0.80	0.59	Delete: Qualitative suggestion, low CVI scores (< 0.80) by HPs and expert patient
CS1	Remove: may resonate stigma	51	Good	0.63	0.25	46	Excellent	0.85	0.69	Delete: Qualitative suggestion and may be perceived as stigmatizing question
CS2	Revise: may resonate stigma	50	Excellent	0.80	0.6	45	Excellent	0.87	0.73	Delete: May be perceived as stigmatizing question and low CVI score (0.80) by participants
CS3	Keep	50	Excellent	0.80	0.6	47	Excellent	0.85	0.7	Keep and revise
CS5	Revise: specify the close person	52	Good	0.73	0.46	44	Excellent	0.93	0.86	Keep and revise
CSN6	Remove: redundancy CS3	46	Excellent	0.89	0.78	45	Excellent	0.87	0.73	Delete: Qualitative suggestion, low CVI score by expert patients (< 0.80), and redundancy with CS3
CIFN1	Keep	52	Good	0.73	0.46	48	Excellent	0.90	0.79	Delete: Very low CVI score by patients (< 0.80) and may create wrong impression on patients
CIF2	Keep	51	Good	0.65	0.29	48	Excellent	0.92	0.83	Keep and revise
CIF3	Revise: phrasing of the question	52	Excellent	0.79	0.58	46	Excellent	0.83	0.65	Keep and revise
CIF5	Remove: Might have different meaning	52	Excellent	0.88	0.77	45	Excellent	0.93	0.87	Delete: Qualitative suggestion and might have different meaning by expert patients
CIF6	Keep	52	Excellent	0.88	0.77	47	Excellent	0.98	0.96	Keep and revise
PKB3	Revise: mention examples	52	Excellent	0.88	0.77	46	Excellent	0.98	0.96	Keep and revise
PKB4	Revise: mention examples-	51	Excellent	0.94	0.88	48	Excellent	0.98	0.96	Keep and revise
PKB6	Keep	52	Excellent	0.85	0.69	47	Excellent	0.94	0.87	Keep and revise
PKB7	Keep	52	Excellent	0.87	0.73	47	Excellent	0.89	0.79	Delete: Low CVI score by expert patients (< 0.80)
PKB8	Remove: It may give wrong meaning to patients	52	Excellent	0.88	0.77	47	Excellent	0.89	0.79	Delete: Qualitative suggestion, low CVI patient scores (< 0.80) and can give wrong meaning to patients
PKB9	Remove: It may give wrong meaning to patients	52	Excellent	0.87	0.73	48	Excellent	0.88	0.75	Delete: Qualitative suggestion, low CVI patient scores (< 0.80) and can give wrong meaning to patients
PR1	Keep	51	Excellent	0.86	0.73	48	Excellent	0.92	0.83	Delete: Redundancies of concepts & low CVI score (< 0.80) by expert patients
PR8	Keep	52	Excellent	0.92	0.85	48	Excellent	0.96	0.92	Keep and revise

**Table 3** (continued)

Item Code	Participants' qualitative judgment	Item clarity scores			Relevance CVI			Final decision and reasons for deleted items		
		N	Kappa <sup>2</sup>	FVI <sup>1</sup>	FVR <sup>2</sup>	N	Kappa <sup>2</sup>	CVI <sup>1</sup>	CVR <sup>3</sup>	
PRP10	Keep	51	Excellent	0.84	0.69	47	Excellent	0.89	0.79	Keep and revise
PRN11	Keep	51	Excellent	0.94	0.88	47	Excellent	0.96	0.91	Keep and revise
PRN12	Remove	52	Excellent	0.90	0.81	47	Excellent	0.91	0.83	Delete: Qualitative suggestion, low CVI patient scores (< 0.80) & can give wrong meaning to patients
PRN13	Keep	49	Excellent	0.86	0.71	47	Excellent	0.94	0.87	Delete: Redundancies of concepts with other items and lowest CVI scores (< 0.80) by expert patient
PSF1	Keep	52	Excellent	0.92	0.85	47	Excellent	0.91	0.83	Keep and revise
PSF3	Keep	52	Excellent	0.87	0.73	46	Excellent	0.91	0.83	Keep and revise
PSF6	Remove	51	Excellent	0.84	0.69	46	Excellent	0.87	0.74	Delete: Qualitative suggestion and it might wrongly be interpreted by patients
PSR1	Revise	50	Excellent	0.80	0.6	46	Excellent	0.93	0.87	Keep and revise
PSR2	Keep	49	Good	0.71	0.43	44	Excellent	0.89	0.77	Keep and revise
PSR4	Keep	50	Excellent	0.88	0.76	44	Excellent	0.93	0.86	Keep and revise
PSR5	Revise: add justification	51	Good	0.75	0.49	46	Excellent	0.85	0.69	Keep and revise
PSR8	Keep	52	Excellent	0.79	0.58	47	Excellent	0.91	0.83	Delete: Redundancies of concepts with other items and lowest CVI scores (< 0.80) by expert patient
PSR12	Revise: Consult expert without stopping the treatment	52	Excellent	0.94	0.88	47	Excellent	0.98	0.96	Keep and revise
PSR14	Revise: phrasing of the questions	50	Excellent	0.88	0.76	43	Excellent	0.95	0.91	Keep and revise
PSR18	Revise: mention examples—patience, calmness	51	Excellent	0.92	0.84	47	Excellent	0.94	0.87	Keep and revise
PSR19	Remove: redundant with other specific questions	52	Excellent	0.79	0.58	46	Excellent	0.87	0.74	Delete: Qualitative suggestion, low CVI scores (< 0.80) by expert patients and redundancies of concepts
PSR23	Keep	52	Excellent	0.83	0.65	46	Excellent	0.87	0.74	Keep and revise
PSR28	Remove: might transmit wrong message	52	Excellent	0.85	0.69	47	Excellent	0.89	0.79	Delete: Qualitative suggestion might be wrongly interpreted by patients and low CVI score (< 0.80)
PSMB1	Revise: Change the question to responsibility	51	Excellent	0.82	0.65	46	Excellent	0.89	0.78	Keep and revise
PSMB2	Keep	50	Excellent	0.80	0.6	44	Excellent	0.91	0.82	Keep and revise
PSMB4	Keep	52	Excellent	0.88	0.77	47	Excellent	0.89	0.79	Keep and revise
PSMB7	Keep	52	Excellent	0.92	0.85	45	Excellent	0.91	0.82	Keep and revise
PSMB8	Revise: add phrase what available at home?	51	Excellent	0.86	0.73	46	Excellent	0.85	0.69	Keep and revise
PSMB9	Remove	50	Excellent	0.80	0.6	46	Excellent	0.85	0.69	Delete: Qualitative suggestion and it might be discriminating question
PSMB10	Remove: redundancy PSMB2	43	Excellent	0.84	0.67	40	Excellent	0.88	0.75	Delete: Redundancies with another item (PSMB2)
PSMB12	Keep	50	Excellent	0.76	0.52	43	Excellent	0.84	0.67	Keep and revise
PSMB14	Keep	51	Excellent	0.90	0.8	46	Excellent	0.98	0.96	Keep and revise



Table 3 (continued)

Item Code	Participants' qualitative judgment	Item clarity scores			Relevance CVI			Final decision and reasons for deleted items		
		N	Kappa <sup>2</sup>	FVI <sup>1</sup>	N	Kappa <sup>2</sup>	FVR <sup>2</sup>	CVI <sup>1</sup>	CVR <sup>3</sup>	
PSMB15	Revise: mention examples	50	Excellent	0.90	45	Excellent	0.82	0.91	0.82	Keep and revise
PSMB19	Revise: mention examples	51	Excellent	0.82	44	Excellent	0.95	0.98	0.95	Keep and revise
PSMB20	Remove: might reduce facility visit	51	Excellent	0.78	45	Excellent	0.91	0.96	0.91	Delete: Qualitative suggestion and might be wrongly interpreted as it may reduce facility visits
PSMB21	Keep	50	Excellent	0.98	44	Excellent	1.00	1.00	1	Keep and revise
PSMB22	Keep	50	Excellent	0.96	46	Excellent	0.91	0.96	0.91	Keep and revise
PSMB23	Keep	49	Excellent	0.90	45	Excellent	0.78	0.89	0.78	Keep and revise
PSMB24	Keep	51	Excellent	0.94	44	Excellent	0.95	0.98	0.95	Keep and revise
HS1	Remove	49	Excellent	0.78	46	Excellent	0.52	0.76	0.52	Delete: Qualitative suggestion, low CVI score (< 0.80) by expert patient and not adequate to measure quality of life
HS3	Remove	49	Good	0.69	45	Excellent	0.51	0.76	0.51	
HS4	Remove	51	Excellent	0.88	46	Excellent	0.91	0.96	0.91	
HSN5	Remove	50	Good	0.74	46	Excellent	0.69	0.85	0.69	
				S-FVI/Ave <sup>3</sup> = 0.82				S-CVI/Ave <sup>3</sup> = 0.90		
				S-FVR <sup>4</sup> = 0.64				S-CVR <sup>4</sup> = 0.81		

<sup>1</sup> I-CVI = Item Content Validity Index

<sup>2</sup> Kappa, described by Cicchetti and Sparrow (1981) and Fleiss (1981): Fair k = 0.40–0.59; – Good k = 0.60–0.74; and Excellent k > 0.74

<sup>3</sup> CVR = Content Validity Ratio

<sup>4</sup> S-CVI/Ave = Overall Scale CVI via Averaging calculation method

Overall Scale CVR via Averaging calculation method

describes a summarized overview of the comments and suggestions provided by the participants.

#### ***Variation in item values of CVI and qualitative judgements of items***

The I-CVI values exhibited significant variation among the respondent groups. HIV program experts or academic researchers assigned higher I-CVI values, compared to other participants (i.e. 54 out of the 63 items were labeled as 100% relevant). Low I-CVI scores which are below 0.70 were assigned to seven items only by HIV patients. Suggestions made on how to manage items based on I-CVI values and qualitative judgement were not always in agreement. As presented in Table 3, some items with high I-CVI scores were suggested for removal based on qualitative judgment. Also, some items which were suggested for retention or revision by qualitative judgment had low I-CVI values.

#### ***Chance agreement***

Chance agreement approached zero for all items, and the values for the Kappa statistic coincide with the I-CVI values. All the items have kappa value of  $>0.74$  which is designated as excellent for relevance of the items. Table 4 shows the kappa of items for clarity and relevance.

#### ***Revision and item selection for second round face and content validation***

The revision of items in the HIV-SM LMIC tool was guided by the I-CVI values and qualitative suggestions from participants. Based on the overall I-CVI values, no items required deletion, and only two items needed revision: one item on 'perceived health status' and one item on 'perceived future health statuses'. Suggestions of respondents encompassed changes in phrasing, Amharic translation, contradictory questions, incorrect interpretations, perceived discriminatory items, overlapping content, and others as outlined in Table 3.

Out of the initial 63-items, 37 items were revised and selected for the second round of face and content validity. I-FVI values were utilized as supportive evidence to revise items. The 26 items were dropped from next level of validation process. A critical review of item importance was conducted in line with the study's objective before the removal of the item. The 63-items HIV-SM LMIC tool including scores and decision is included in the supplementary file (Annex 01), and a summary of the adaptation presented is summarized in Table 3.

#### ***Round two face and content validity***

The 37-item HIV-SM LMIC tool, resulting from the first-round face and content validity process, underwent validation by nine participants to assess clarity and relevance.

Like the first round, questions that were used to evaluate face and content validity mirrored those from the initial phase. Nine participants rated each item based on its relevance and clarity, providing suggestions for improvement, including contextualization, removal, or retention. The decision-making process regarding item retention and revision was guided both by the CVI and FVI values, along with input from the participants. Among the 37 items, only two scored below 0.70 on the CVI, four fell between 0.70 and 0.79, ten ranged from 0.80 to 0.90, and the remaining 21 items achieved a perfect score of 1 or 100% relevance.

Five items out of the initial 37 were removed from the HIV-SM LMIC tool during the next level of validation process. Three items were eliminated due to low CVI scores ( $<0.70$ ) and overlapping concepts with other items, while the remaining two items were dropped based on qualitative suggestions from participants. The remaining 32 items, along with their Amharic translations, were revised following the suggestions of the participants. The 37-item HIV-SM LMIC tool, along with its corresponding Amharic version, CVI scores, and decisions, is included in the supplementary file (Annex 02), and a summary of the validation results is summarized in Table 4.

#### ***Summary of selection of items***

The item generation process resulted in a total of 63 items for the HIV-SM LMIC tool. Following the first round of face and content validation, 26 items were removed based on their relatively low CVI scores and qualitative feedback suggesting deletion or merging. This refinement resulted in a 37-item HIV-SM LMIC tool. As indicated in Table 5, nine items (52.3%) from the contextual dimension, 10 items (38.5%) from the process dimension, and all 4 items (100%) from the distal outcome dimension were removed. In the second-round face and content validation, 5 additional items (2 from contextual, 1 from process and 2 from proximal outcome dimension) were dropped based on CVI scores and qualitative suggestions, resulting in a final 32-item HIV-SM LMIC tool.

#### ***Discussion***

The aim of this study was to develop a comprehensive self-management questionnaire for people living with HIV (HIV-SM LMIC tool), intended for use in research and healthcare in low- and middle-income countries, involving the assessment of face and content validity of the questionnaire. To our knowledge, this is the first study to establish a contextualized and validated (i.e. face and content) HIV-SM LMIC tool. The initial development process of the HIV-SM LMIC tool started with 63 items organized into four dimensions of the IFMST,

**Table 4** Second round validation of HIV-SM LMIC tool and items selection

Code	CVI	Final decision	Qualitative reasons or comments
CCS1	0.89	Delete	It will be affected by time. The patient may not face these symptoms at time of assessment, but this doesn't mean that it did not occur previously or will not occur in the future
CCS2	0.89	Delete	Side effects depend on the types of medicine
CP1	0.89	Keep & revise	The patient might not be completely aware what the standards of service are and as such might under or overestimate the HF services. Translation problem
CS3	1.00	Keep	
CS5	0.89	Keep & revise	Make all questions for both sex? Translation problem
CIF2	1.00	Keep	
CIF3	0.78	Keep	
CIF6	1.00	Keep & revise	Need explanation in brackets.—physically active. Translation problem
PKB3	1.00	Keep & revise	Question might need some sort of reference line be it in utility or outcome as it bares to be more subjective
PKB4	1.00	Keep & revise	What does it mean? I mean what is expected to know from the user side?
PKB6	0.78	Keep & revise	How does this go with measuring knowledge and belief? Translation problem
PR8	1.00	Keep	
PR10	0.89	Delete	Merge with PR8
PRN11	1.00	Keep & revise	Would trust always be a good way to note agreement, acceptance, or utility? Translation problem
PSF1	0.89	Keep & revise	This is more inclined to social capital, than social facilitation/support. Translation problem
PSF3	1.00	Keep	
PSR1	0.78	Keep & revise	Means? By themselves or by someone?
PSR2	1.00	Keep	
PSR4	1.00	Keep & revise	Maybe a way to quantify missed dose frequencies might be helpful
PSR5	0.89	Keep & revise	Patients may start-stop-start their medication? If not, asking the frequency may be less relevant
PSR12	0.89	Keep	
PSR14	1.00	Keep & revise	Translation problem and not clear
PSR18	1.00	Keep & revise	Translation issues and important to elaborate what types for spirituality
PSR23	1.00	Keep & revise	Not a simple item?
PSMB1	0.89	Keep & revise	"The knowledge of your current condition" is not clear and translation problem
PSMB2	0.78	Keep	
PSMB4	0.67	Delete	Redundant
PSMB7	1.00	Keep & revise	What type of discipline is needed to do exercise? Translation problem
PSMB8	1.00	Keep	
PSMB12	1.00	Keep	
PSMB14	0.67	Delete	Redundant
PSMB15	1.00	Keep & revise	Add the example listed in Amharic version to English version? Translation problem
PSMB19	1.00	Keep	
PSMB21	1.00	Keep	
PSMB22	1.00	Keep	
PSMB23	1.00	Keep & revise	Quantification appears vague
PSMB24	0.89	Keep	

namely, contextual, process, proximal outcome, and distal outcomes, drawing upon insights from the preceding two papers [29, 30]. This process of development and validation resulted in a 32 items HIV-SM LMIC questionnaire.

A significant proportion of items were dropped, primarily from the contextual dimension, followed by the process dimension. The contextual dimension of the IFMST primarily encompasses external factors beyond

the patient's control, which can nonetheless influence the patient's self-management through its effect on the process dimension [32]. For instance, access to health-care facilities (e.g. *you agree that the health facility offers the services you require most of the time, such as lab tests for viral load or CD4?* የጤና ተቋሙ ከብዛኛውን ጊዜ የሚፈልጓቸውን አገልግሎቶች አንደ የቫይረስ መጠን ወይም CD4 ያሉ የላቦራቶሪ ምርመራዎች አንደሚሰጡ ይስማማሉ?) access to is not a modifiable factor by the patient. Moreover, some

**Table 5** Number of items generated and selected for further validation process

Dimension of the IFSMT framework	Domains of IFSMT framework	Total items	First round face & content validity		Second round face & content validity	
			Remove	Selected for 2nd round	Remove	Selected for subsequent validation
<b>Contextual:</b> Risk and protective factors that affect self-management practices	Condition specific factors	3	1	2	2	0
	Physical or facility environment	4	3	1	0	1
	Social environment	5	3	2	0	2
	Individual and family related factors	5	2	3	0	3
	<b>Sub-total</b>	<b>17</b>	<b>9</b>	<b>8</b>	<b>2</b>	<b>6</b>
<b>Process:</b> Knowledge, beliefs, social engagement, and self-regulation that impacts SM	Knowledge and beliefs	6	3	3	0	3
	Relationships with health service providers	6	3	3	1	2
	Social facilitation	4	1	3	0	3
	Self-regulation skills and abilities	10	3	7	0	7
	<b>Sub-total</b>	<b>26</b>	<b>10</b>	<b>16</b>	<b>1</b>	<b>15</b>
<b>Proximal outcome</b>	Self-management behaviors	16	3	13	2	11
	<b>Sub-total</b>	<b>16</b>	<b>3</b>	<b>13</b>	<b>2</b>	<b>11</b>
<b>Distal outcome</b>	Health status (quality of life)	4	4	0		
	<b>Sub-total</b>	<b>4</b>	<b>4</b>	<b>0</b>		
<b>Total items</b>		<b>63</b>	<b>26</b>	<b>37</b>	<b>5</b>	<b>32</b>

items in this dimension may create wrong interpretation and might be stigmatizing culturally (*E.g. Do you think that your illness decreased the ability to work and carry out daily activities? ህመምዎ የዕለት ተዕለት ከንቀስቃሌን ከና የመሥራት ችሎታን ከንደቀነሰ ይመስልዎታል?*). Participants might also perceive items in this dimension as distant from the core essence of self-management, thus suggesting that items within this dimension may be given lower priority for selection.

Most of the dropped items within the process dimension were identified in two domains: 'knowledge and beliefs' and 'relationships with healthcare providers'. The items were dropped due to two key reasons: the insufficient number of items for a comprehensive assessment of knowledge and concerns that patients might misinterpret certain items. For instance, items developed to assess knowledge and beliefs, such as “*Do you believe that HIV infection is caused by evil spirits? የኬችክደሺ በሽታ በከፋ መናፋስት/ሀጥያት ምክንያት ነው የሚመጣ ነው ብለው ያምናሉን?*” and “*Do you believe you can stop taking HIV medications when you start feeling better? ህመሙ ሲሻልዎት የኬችክደሺ መድሃኒቶችን መውሰድ ማቆም ይቻላል ብለው ያምናሉን?*” were noted by participants as potentially being misinterpreted by patients. These comments are significant, particularly considering the low health literacy among the public in Ethiopia [37].

All 63 items included in the initial draft of the HIV-SM LMIC tool received high I-CVI scores ranging from

0.76 to 1.00. Only few items were dropped because of I-CVI values less than 0.80. We proceeded to scrutinize the I-CVI scores across different respondent groups and carefully considered the qualitative feedback provided by the study respondents. Among the three respondent groups, particular attention was given to the I-CVI values provided by HIV patients because of their lived experience of challenges encountered. Furthermore, service users (i.e. HIV patients) offer a unique perspective, sometimes diverging from that of other participants, yet crucial for the validation of a tool as previously demonstrated [38, 39]. Consequently, the authors recommended the inclusion of service users' views and perspectives from the initial stages of tool validation. The findings of this study also revealed that the relevance scores or I-CVI values provided by patients were generally lower than those scored by HIV program experts and healthcare professionals. The average CVI index score by the HIV patients was 0.83 whereas it was 0.93 by HIV expert and health professionals. Thus, the final decision in the current study regarding whether to retain or drop an item was to a large extent based on the I-CVI scores provided by HIV patients, qualitative comments, and importance of the item.

### Strengths and limitations

A major strength of the current study is the use of sound psychometric evaluation methods to develop

a context-specific tool. This resulted in four main strengths of this study. Firstly, the input for item generation was provided by the two studies that assessed the need for and importance of self-management for people with HIV from the perspective of patients and health care providers and experts which employed the IFSMT model [29, 30]. Secondly, we engaged a total of 61 respondents in two rounds of face and content validation, surpassing the maximum number of participants recommended by various authors [34, 35]. This higher number of respondents was intentional to encompass heterogeneous groups to capture more diverse perspectives given the complexity of the topic. Thirdly, we incorporated service users (HIV patients) as participants of items, in line with previous recommendations [38, 39]. Fourthly, both the Amharic (the common language in Ethiopia) and English versions of the HIV-SM LMIC tool underwent validation in both rounds of face and content validity. This approach facilitated the contextualization of items (in the Amharic version) according to societal culture, accelerating the tool's adoption by other researchers and easing data collection in subsequent validation processes.

One limitation is that the I-CVI scores for the contextual (first) and outcome (last) dimensions of the tool were relatively lower compared to the scores in the other domains, although they did not indicate low CVI scores. This may reflect a dip in concentration while completing the tool and to minimize this at least three days were allowed for the respondents to return. As the result it did not affect the selection of the items.

### Future perspectives and clinical implications

Research on HIV self-management in low- and middle-income settings is very limited, and many reviews of the use of self-management for HIV do not include studies conducted in the African Region [17, 40]. Context-specific self-management interventions in low- and middle-income countries need context-specific interventions and tools [30]. Currently, many clinicians in low- and middle-income countries engage in provider-centered service delivery [17, 30, 41]. The HIV-SM LMIC tool outlined in this paper has the potential to enable clinicians to facilitate a shift towards more patient-centered care in low- and middle-income countries, empowering patients to actively manage their condition and fostering the development of interventions tailored to local contexts. Not only clinicians, but also HIV patients and researchers in the field may find it valuable. However, further research into its construct and criterion validity and reliability is recommended

before its use. Moreover, it is recommended for future studies to assess cross cultural validity of the final tool.

## Conclusions

In conclusion, a comprehensive HIV-SM LMIC tool tailored for HIV patients in low- and middle-income countries was developed following rigorous psychometric evaluation process. The overall face and content validity of the 63-item HIV-SM LMIC tool for relevance and clarity were deemed excellent. However, based on qualitative suggestions and relevance scores provided by HIV patients, 26 items in the first round and 5 items in the second round were dropped from the next level of validation, resulting in the 32-item HIV-SM LMIC tool.

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12879-025-10876-9>.

Supplementary Material 1.

Supplementary Material 2.

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## Authors' contributions

MQ: Conceptualization, Methodology, Software, Data Curation, Visualization, Writing-Original Draft. WL: Conceptualization, Supervision, Resources, Writing-Reviewing and Editing, Funding acquisition. DL: Visualization, Data Curation, Visualization. ZH: Methodology, Software, Data Curation. SH: Resources, Writing-Reviewing and Editing, Funding acquisition.

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## Data availability

The data that support the findings of this study are available from World Health Organization ([https://worldhealthorg.shinyapps.io/mpx\\_global/](https://worldhealthorg.shinyapps.io/mpx_global/)).

## Declarations

### Ethics approval and consent to participate

The study protocol was reviewed and approved by the Hawassa University College of Medicine and Health Sciences Institutional Review Board (IRB). Ethical approval letter was written on 07/05/2019 with the reference number of Ref. No. IRB/216/11. The approval of the ethics was in accordance with the Declaration of Helsinki. The data were collected and analyzed anonymously. Informed audio consent (available on tape recording) was taken from the study participants before starting the data collection.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

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