



Original Article

Cultural Adaptation of Patient Health Questionnaire-9 in Hindi for Use with Patients with Cancer in Community Palliative Care Settings

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ABSTRACT

Objectives: Patient Health Questionnaire-9 (PHQ-9) in Indian settings is yet not very often used in palliative care with the Hindi-speaking population. The Hindi version of PHQ-9 is available but its cultural adaptation to the Hindi-speaking population in North India receiving palliative care services is required to be tested. PHQ-9 as a depression screening questionnaire may help to identify depression symptoms among patients with cancer. This study aimed to examine the cultural equivalence of PHQ-9 Hindi for use with patients with cancer receiving palliative care services in North India.

Material and Methods: Based on the standard methodology of translation and adaptation of the scale, the following process was used: (i) Two focused group discussions with 17 experts working in a cancer palliative care setting, (ii) qualitative interviewing with 11 patients, and (iii) research team review. All interviews were audio recorded, transcribed, and item-wise content analysis was conducted.

Results: A few difficult phrases in the original PHQ-9 were 'dilchasti', 'avasadgrast', 'kam urja', 'nakaam', 'parivar ko neecha dhikhana' and 'ashthir' which were changed to 'Kam Mann Lagna', 'Mann Dukhi hona, kamjori, saksham nahi hain' 'asafal', 'Parivar ko nirash karna' and 'bechain,' respectively. Two items, namely no. 6 and 8 were changed to shorten the length for appropriately conveying the meaning.

Conclusion: Hindi language involves various dialects which change from region to region bringing variations in understanding the meaning of the words. It is recommended that culturally equivalent scales are used in practice and research. PHQ-9 is now culturally adapted for the Hindi-speaking population in North India. PHQ-9 will help identify depressive symptoms at an early stage. Psychometric testing of PHQ-9 is underway.

Keywords: Patient health questionnaire-9, Cultural adaptations, Linguistic validation, Translation, Patient-reported outcome measure, Depression

INTRODUCTION

Palliative care in India began almost four decades ago but the service structure is still evolving. In Indian settings, palliative care services are mainly directed to patients with cancer as palliative care has been made a part of 'Mission Flexipool' under the National Health Mission under the umbrella of non-communicable disease control programmes. The terminal cases of cancer are one of the major target beneficiary groups under the National Programme for Palliative Care.^[1] These services are provided through various models of palliative care, namely (i) pain and palliative medicine centres, (ii) home care units of the hospitals, (iii) day care centres, (iv) hospice care, and (v) community-based home care model. In India, community-based palliative care services are mainly provided by charity

organisations or home care units of hospitals. A proactive approach is being used wherein a multidisciplinary team of professionals consisting of a doctor, nurse, and counsellor visits the patient's home and offer symptom management and psychosocial support services to patients and their family. Patients with cancer have numerous physical and emotional concerns which may give rise to unresolved anxieties and depressive symptoms.^[2,3] Literature suggests that the prevalence of anxiety among cancer patients ranges from 1.4%^[4] to 37%^[5,6] and depression from 4.5% to 58%.^[2,6,7] Patients with untreated depression or anxiety may be less likely to continue good health habits and may withdraw from family or other social support systems complicating their situation.^[3] It is widely acknowledged that assessing patients' feelings and symptoms are important component

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of patient-centred care and contributes to improving their health-related quality of life.^[8-11] Patient-reported outcome measures (PROMs) are well suited for objective assessment as patients report their concerns in a guided manner leaving less scope for missing concerns.^[12-15] However, it is important that PROMs are target language-specific and that their cultural equivalence and appropriateness are assessed before they are put into practice.^[16-20] The cross-cultural adaptation of an instrument requires a careful linguistic translation including cultural equivalence and psychometric validation following the standard guidelines but it is essential to ensure that the translated and validated version remains similar to the original tool to allow data pooling from cross-cultural and multinational studies.^[17,21-23]

In Indian settings, a few instruments, namely, Health Questionnaire, Depression, Anxiety and Stress Scale Hospital Anxiety and Depression Scale, General 21, and Patient Health Questionnaire-9 (PHQ-9) are available in Hindi language and demonstrated their use with patients with cancer but to the best of our knowledge, none of the scales is yet validated for use in cancer community palliative care setting. In community palliative care settings, the majority of the patients are at the advanced stage of their cancer with high symptom load which requires a brief PROM appropriate to the setting. The PHQ-9 Hindi version, though is a brief instrument, but has not been tested for Indian community palliative care settings. The cultural equivalence of the Hindi version of PHQ-9, its appropriateness, and validity with the Hindi-speaking population in North India receiving palliative care services is required to be tested. This research aims to assess the cultural equivalence of PHQ-9 Hindi for use with patients with cancer receiving community palliative care services in North India.

Setting

The research was implemented by one of the NGOs providing palliative care services to patients with cancer in a community setting in North India. Ethics permission was obtained by the Institutional Ethics Committee-Human Research of the concerned NGO through a letter dated 23 May 2022.

MATERIAL AND METHODS

We obtained permission for cultural adaptation and psychometric testing of PHQ-9 from the original developers of the scale through an email dated 3 May 2022. Based on the standard methodology of translation and adaptation of the scale by the European Organisation of Research and Treatment of Cancer and PROM guidelines,^[17,18,24] we used the following stages for testing cultural equivalence and adaptation of the PHQ-9 Hindi version. We skipped the back-and-forth translation stages as the scale was already available in the target language and shared by the original developer to carry on further cultural adaptation and psychometric validation. The three-stage process was followed:

- Stage I: Cognitive interviewing with experts (professionals from the field)
- Stage II: Cognitive interviewing with patients
- Stage III: Research team review.

Stage I cognitive interviewing with palliative care professionals through focus group discussion (FGD)

Two FGDs were conducted with professionals having expertise in the field of palliative care. Professionals working with palliative care teams of the NGO offering palliative home care services were invited telephonically for the FGD. Those agreeing to participate were invited to FGD in the NGO head office.

A total of 17 professionals participated in FGD, one group consisted of eight professionals while another group had nine professionals. An FGD guide was prepared to discuss and analyse each item of the original translation. The FGD guide aimed to explore any difficult word, comprehension of the item, if the word conveys the appropriate meaning to the target patient group, how would professionals like to change the word or add any word to convey a better meaning of the given phrase in the original version [Appendix 1]. The specific questions in FGD included: 'any item difficult to understand', 'Why does the word look difficult or what meaning does the word communicate' and 'How would you like to replace the word or like to add any word to give the same meaning when compared to the original English item'. The discussion was facilitated by PI (TB) as moderator, audio recorded, in addition, and hand recorded by other researchers (NA, AP, and PC). Each FGD took about 1 and ½ hours. TB and NA listened to the item-wise audio recording repeatedly and supplemented the same with hand notes for analysis.

Stage II: Cognitive interviewing with patients through face-to-face interviews

A total of 11 Hindi-speaking adult patients with cancer receiving home-based palliative care services were interviewed using an in-depth interview guide at their homes [Appendix 2]. Prior verbal permission was sought by the treating team through telephone calls, those agreeing to be interviewed were visited by the PI along with the treating team at the patient's convenience time and interviewed at their home. An in-depth interview guide was prepared to understand the patient's comprehension of each item, any difficult word to understand, how they would like to change the word, and suitability of the item to respond to the given response categories. Patients were also asked to compare the ease of understanding between the original PHQ Hindi with the changes introduced in the items after FGD with professionals. All interviews were conducted by the single researcher (TB) and interviews were stopped after interviewing a sample of 11 patients as saturation in

responses was achieved. All interviews were tape-recorded and transcribed verbatim for item-wise content analysis.

Stage III: Research team review

The PI (TB) and Co-PI (NA) discussed item-wise responses of the professionals and patients comparing the same with the original Hindi PHQ phrase until a consensus was achieved to effect changes in the PHQ-9 phrases. A final adapted version was produced which is given in [Appendix 3].

Sample and sampling procedures

Professionals with at least 1 year of experience in the palliative care field were invited to participate in FGD. A total of 11 adult Hindi-speaking patients (>18 years) with a confirmed diagnosis of cancer were recruited through non-probability sampling techniques from home care teams as well as the day-care centre of the organisation. Patients from home care teams were recruited by the team counsellor who telephonically obtained consent from the patient while patients coming to the day-care centre gave in-person consent to the co-PI (AP). Patients were then interviewed by the PI at a mutually convenient time in the patient's home or day-care centre of the organisation.

Analysis

All interviews were audio recorded and later transcribed with the help of student volunteers. The researchers independently cross-checked the transcription randomly to ensure rigour in the process. Any errors were corrected after repeated listening to the same track by two researchers together. Item-wise content analysis was used for process recording and presenting results as well as discussion to facilitate transparency in the findings.

RESULTS

A total of 17 professionals and 11 patients participated in FGD and in-depth interviewing, respectively. Details of the professionals and patient participants are given in [Tables 1 and 2], respectively. The multidisciplinary professional team including doctors, nurses, counsellors and social workers participated in FGD. Ten professionals had more than 10 years of work experience.

Patients who participated in the study were diagnosed with cancer at least a year ago, most were working and educated at least till 8th standard. Patients with different cancer types were included in the study.

A few of the items which were difficult to understand, comprehend and conveyed ambiguous meanings in the original Hindi version of PHQ-9 were – ‘*dilchaspi*’, ‘*maza aana*’, ‘*kuch karne mein*’, ‘*avasadgrast*’, ‘*kam urja hona*’, ‘*nakaam insaan*’, ‘*parivaar ko neecha dikhaya*’ and ‘*asthir*’. A few phrases that though considered appropriate by the professionals but could not convey clear meaning to the patients were – ‘*Rozmarrah*’ which was changed to ‘*rojana*’ meaning daily. Patients also

Table 1: Characteristics of the professionals in FGD.

Professional discipline (N)	Number of years of experience			
	<5	5–10	10–15	15+
Medicine (2)	1	1		
Nursing (2)				2
Counsellor supervisor/managers (5)		1	2	2
Field level counsellors (6)	2	2	2	
Social worker (2)			1	1
Total	3	4	5	5

FGD: Focus group discussion

Table 2: Profile of the patients for in-depth interviewing.

Characteristics	Frequency
Age (Median)	50 (Min 19, Max 70)
Gender	4 F, 7 M
Education	
Below VIII standard (8–9 years of schooling)	3
Secondary education (10–11 years)	2
Sr. Secondary (12–13 years of schooling)	2
Graduate (Bachelor's degree)	4
Occupation	
Homemaker	3
Daily wager	2
Pvt Job and self-employed (current and retired)	4
Student, unable to work	2
Cancer Diagnosis	
Breast cancer	2
Stomach and genital organs	4
Multiple myeloma	2
Brain tumour, buccal mucosa, and skin	3
Length of the disease	
<1 year	2
3–5 years	6
7–10 years	3

felt the use of ‘*nakaam*’ and ‘*parivar ko neecha dikhana*’ was offensive and inappropriate in their cultural context.

Minor changes were made in items no. 1, 2, 4, and 6 while major changes were made in item no. 7 and 8. A single word, namely ‘*Bahut*’ meaning ‘very much’ was added in item no. 5 to emphasise the given behaviour in the original item. A synonym for a single word, namely ‘*tareeke se/tareh se*’ instead of ‘*dhang se*’, and the tense orientation of two words, namely ‘*mar jaye*’ instead of ‘*mar jate*’ and ‘*Achha hoga*’ instead of ‘*Achha hota*’ in item no. 9 were changed. Thus, the sentence structure in item no. 9 was changed to future orientation instead of past orientation as given in the original PHQ. Item no. 3 was retained as it is. Items no. 3 and 5 in the PHQ questionnaire were comprehended well by the patients.

The comprehension of item no. 7 by the patients was directed towards entertainment instead of concentration thus requiring explanation. Item no. 7 was considered incomplete both by professionals and patients in the present context so other words such as 'mobile chalana', 'gana sunna' and 'kitaab padhna' were introduced in the item. Item no. 8 was found to be very long to recall for the patient. The researcher had to break the given item into small parts to help patients retain the comprehension of all the words in the sentence; even then the patients were not able to recall the entire meaning of the sentence. This reflected the need to cut short a few words in item no. 8. The research team deliberated at length during the review stage and decided to drop a few words to

shorten the given item from 32 words to 21 words. In the central item given at the end of the questionnaire, 'self-care' was missing which was an important and foremost task for the patient before doing any other tasks of daily routine. Thus, the phrase 'khud ka dhyaan rakhna' was added to the given item.

DISCUSSION

We presented a culturally adapted version of PHQ-9 for use with patients with cancer in north Indian palliative care settings. The Hindi version of PHQ-9 which has previously shown good reliability and validity^[9,10,21,25] was presented to both medical professionals and patients to test its cultural

Box 1: Challenging phrases from the original PHQ and their equivalent phrase in the adapted version.

Original PHQ item No.	Original PHQ phrase	Problem reflection	Narratives by professionals in palliative care	An equivalent Hindi phrase suggested
Item No. 1	Dilchaspi or Maza aana	Fun orientation	'May not be understood by every one as its not very commonly used in day-to-day language' and 'Carry a fun orientation meaning.'	Kam man lagna
Item No. 1	Kuch karne mein	Sounds incomplete, like ... doing what???	We should add the word 'kaam' to give the item a better meaning. 'Rozmarrah ke kuch kaam karne mein Bahut kam man lagna'	Rozmarrah ke kuch kaam karne
Item No. 2	Avasadgrast	Not commonly used word in day-to-day life	'The word is not used in daily life.' 'Even we don't use this word commonly. Instead, any word that a person understands more clearly.' It's a pure Hindi word, not used in day-to-day language, also it's difficult to pronounce	Man dukhi hona
Item No. 4	Kam urja	Not commonly used word in day-to-day life	'It was not an everyday Hindi language word, but rather a Hindi literature word.'	Kamjori
Item No. 5	Jyada khaana	Eating more may not reflect depressive symptoms, but the bodily need to regain lost energy	The item would sound better if we say 'bhookh kam lagna ya bohot zyada khana'	Bahut jyada khana
Item No. 6	Nakaam insan Parivar ko nichaa dikana	Offending words Offending and guilt-inducing	Nakaam insan carries a negative connotation A softer meaning word is required which won't induce negative feelings in patients.	Saksham na hona Asafal Parivar ko nirasah karna
Item No. 7	Akhbaar padhne ya television dekhne	Newspaper reading is getting outdated in today's context Orientation to entertainment sources instead of the required theme of concentration	Incomplete resources in the present cultural context where technology has invaded everyone's life Use a sentence-breaking and emphasising phrase like 'ityaadi' to give importance to the 2 nd part of the item i.e., concentration	Kitaab padhna, mobile chalana to be added to give a comprehensive range ityaadi' added after four options
Item No. 8	Asthir	Not a commonly used word in day-to-day conversation	This is not generally used in daily language. As its synonym bechain is already in the sentence using/so we may drop this word	Bechain kuch kaam ko bahut dheere karna
Item No. 9	Mar jate	Very harsh- gives past orientation	Make it future-oriented instead of past orientation as given currently.	Mar jaye
Item No. 9	Dhang se	Rough meaning word, conveying an informal way of conversation	Tarike/Tareh se is sounding better and more formal	Tareh se

equivalence. Results indicated that words in a few items were not perceived well and reported comprehension difficulty by health professionals and patients. The previous research also reported that the language in a few PHQ items though technically correct but complex and difficult to comprehend.^[25] We reported each item-wise adaptation process along with discussion points forwarded by the professionals and patients for identifying difficult phrases and bringing required alterations in PHQ-9 items [Box 1]. Item-wise comparison of the PHQ-9 original Hindi version with the current adapted version is presented in [Appendix 4].

The first item, namely '*Kuch karne mein bahut kam dilchaspī ya maza aana*' made both professionals and patients uncomfortable. Most of the professionals felt that the word '*dilchaspī*' may not be understood by everyone as it's not very commonly used in day-to-day language. Further, '*dilchaspī*' and '*Maza aana*' both words carry a fun orientation. Instead, professionals suggested words like '*sukoon*' or '*man lagna*', as better alternatives to replace the given words. Another difficult word in item no. 1 was '*kuch karne mein*' as it did not clear what work/task it refers to, which may let a person wonder which work he/she is asked for. The professionals suggested that '*Rozmarrah ke kuch kaam karne main*' to give clear meaning to what is being referred to here and the item was unanimously changed to '*Rozmarrah ke kuch kaam karne mein bahut kam man lagna*'. The changed item when asked the patients, four of them^[4] could not understand the phrase '*Rozmarrah*'. They comprehended it as 'dying every day' and suggested using the word '*Rozana*' instead. Other patients also agreed to the new word, that is, '*Rozana*'. This suggested the change in language shift in India from region to region as migrating people carry their language and culture with varied notions^[26,27] which need to be considered while translating and culturally adapting the items. Thus, the first item was finally adapted as: '*Rozana ke kuch kaam karne mein bahot kam man lagna*'.

For the second item of PHQ was '*Udas, avasadgrast ya nirash mehsoos karna*', professionals felt '*avasadgrast*' is one of the very difficult words as it's not being used in daily life, even educated people do not use this word commonly. The idiomatic problem with this phrase was highlighted by previous researchers^[9,28] too who reported that a literal meaning of the word may not give a simple, actual, and appropriate meaning. A few replacements of this word suggested by professionals were '*dukhi*', '*bebas*', '*majboor*', '*bechain*', '*mann ka bhujha bhujha sa hona*', and '*mann ka dukhi hona*'. Most of the participants later tried to narrow down this list by eliminating a few words like '*bebas*' which was considered as helpless and '*bechain*' as anxiety. The final replacement suggested by professionals was '*Man dukhi hona*'. During patients' interviews, eight participants very clearly indicated that '*avasadgrast*' was beyond their understanding. Thus, the item was changed to '*Udas, mann dukhi hona ya*

nirash mehsoos karna' which was easily understood by patients too.

The third item '*neend aane ya soye rehne mein pareshaani, ya fir bahut adhik sona*' did not report any difficult phrase. The item was comprehended quite well by all the professionals and patients confirming no need for changes in the given original item. In the fourth item, '*thakaan mehsoos karna ya bahut kam urja hona*', the phrase '*urja*' was perceived as difficult by the professionals and patients alike as it was not an everyday Hindi language word instead a Hindi literature word which may not be understood by less educated patients. Few alternatives such as '*takat*' and '*kamzori*' were suggested. All professionals voted for '*kamzori*' as patients generally use this word to raise their concerns about lack of energy. Thus, the item was changed to '*thakaan mehsoos karna ya bahut kamjori mehsoos karna*'. All the patients comprehended the adapted phrases quite well.

The fifth item '*bhookh kam lagna ya zyaada khaana*' though considered fine by all the professionals; they suggested to prefix '*bahut*' with the last word '*zyaada khaana*'. Professionals reasoned that patients with depression might feel either lose their appetite for food or binge eat. In palliative care, patients with cancer usually eat less. Eating more could not be an indicator of depression in this context as it might be recovering from the lost diet. Patients comprehended the original phrase and the adapted phrase equally well but were happy with the adapted version as this posed more emphasis on anything unusual in diet patterns. Thus, the final adapted version was: '*Bhookh kam lagna ya bahut zyaada khana*'.

The 6th item '*Apne bare mein bura mehsoos karna- ya aisa mehsoos karna ki aap nakaam insaan hain aur aapne khud ko aur apne parivaar ko neecha dikhaya hai*' was regarded as a very lengthy item. '*Nakaam*' word was considered offensive as it was attached with the connotation of failure. Professionals felt that a softer meaning word is required which won't induce negative feelings to patients. A few alternatives suggested by professionals were '*bura mehsoos karna*', '*Saksham na hona*' '*asafal*', and '*Kabil nahi*'. Professionals had to refer to the English version of PHQ-9 to choose a meaning-appropriate word, '*asafal*' was chosen unanimously as the best alternative. Another problematic phrase '*parivaar ko neecha dikhaya hai*' might instill a sense of burden and failure in patients. Thus, '*parivaar ko nirash kiya hai*' might be a better replacement which also retains the original meaning. This argument was seconded by one of the patients during in-depth interviewing as he felt offended once the original item was read to him. Other patients also felt the use of '*nakaam*' and '*parivaar ko neecha dikhana*' as offensive and inappropriate in their cultural context. The item was finalised as '*apne bare mein bura mehsoos karna- ya aisa mehsoos karna ki aap asafak hain aur aapne khud ko aur apne parivaar ko niraash kiya hai*'. The responses of the patients who felt offended by the phrases used in the original PHQ-9 Hindi version suggested that

various phrases may carry different meanings and orientations in varied cultures. The phrase in the already available Hindi version had the scope of item bias. Researchers have confirmed that item bias can be produced by many sources such as poor item translation, ambiguities in the original item, linguistic idiosyncrasies, low familiarity, and nuisance associated with the phrase in certain cultures.^[29,30]

'Akhbaar padhne ya television dekhne jaisi cheez par dhyaan dene mein pareshaani' was the seventh item in the original questionnaire. Professionals opined that reading newspapers may not be appropriate in today's context where it has been mostly replaced by mobile or news channels. Thus, other words such as 'mobile chalana,' 'gana sunna' and 'kitaab padhna' might also be added. Thus, the final adapted item was: 'akhbaar padhna, TV dekhna, kitaab padhna, mobile chalana ityaadi par dhyaan dene mein pareshaani.' Patients thought related to the options given in the adapted version; however, it was experienced that instead of a concentration theme, respondents conceptualised items for hobby or entertainment options. A similar problem was also reported by a previous researcher working with PHQ(9) where the literal translation failed to capture the theme of difficulty in concentration.

The eighth item read as 'itna dheeme chalna- firna ya bolna ki logon ka dhyaan jaye ya iska ulta-itna asthir ya bechain hona ki aap samaanya se kaafi zyaada hilte dulte aur chalte firte rahe', the phrase 'asthir' was perceived as a difficult word by the professionals and patients alike as the word is not generally used in daily language. Professionals suggested that words in the item must refer to the behaviour of the patient and not just walking or talking simply. Furthermore, many a time, such behaviour is noticed by the caregiver and not the patient himself, so words must be so framed that even the caregiver can comprehend the same in reference to the patient. Thus, it was suggested to drop subject addressing words like 'aap'. Professionals unanimously suggested changing the item as 'kuch kaam ko bahut dheere karna, dheere chalna firna ya dheere bolna ya bahut zyaada bechain rehna aur samaanya se bahut jyada chalte firte rehna'. In previous research too, 'moving or speaking so slowly that other people may have noticed' was not easily related by the glaucoma patients perhaps suggesting that behaviours such as speaking, tone of voice, and walking around are perhaps not common manifestations of depression in Indian context rather may be disease-related physical symptoms.^[10] The item was shortened to ease the recall process. The final adapted item was: 'itna dheera chalna- phirna, bolna ki logo ka dhyan jaye ya iska ulta jaise bechan rahena ya bahut jyada chalna phirna'.

The 9th item 'Aise vichar ki aap mar jate to acha hota ya kisi dhang se khud ko nuksaan pahunchaana' was perceived as fine with a few minor suggestions by professionals about replacing the word 'jate' with 'jayein', 'hota' to 'hoga' and 'dhang se' to 'tarehse' to make it future-oriented instead

of past orientation. The final item was 'Aise vichar ki aap mar jaye to acha hoga ya kisi tarike se khud ko nuksaan pahunchana'. All patients comprehended the given adapted version well and related with the feelings confirming the acceptance of the item in the scale.

CONCLUSION

The cultural equivalence of PHQ-9 in the Hindi language to be used with Hindi-speaking patients in a North Indian setting was tested. The Hindi version of PHQ-9 is now available to be used in community palliative care settings. [Appendix 3], though psychometric testing of the tool is underway. Based on our experience with these adaptation and validation exercises, we suggest that professionals take due care while administering PHQ-9 in practice. We suggest that lengthy items like no. 6 and 8 need to be broken into parts to help the patient retain comprehension of all the words in the sentence. The interviewer needs to be careful about the appropriate comprehension of item no. 7 by the patient as it meant to capture concentration and not entertainment or hobby which patients may tend to interpret. The implementation of PHQ-9 will help to early screen depression symptoms among patients with cancer in community palliative care settings and quickly refer the patient to the specialist for timely intervention.

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Declaration of patient consent

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Conflicts of interest

There are no conflicts of interest.

Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The author(s) confirm that there was no use of Artificial Intelligence (AI)-Assisted Technology for assisting in the writing or editing of the manuscript and no images were manipulated using the AI.

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Appendix 1

FGD Guide for professionals

Objective:

- To explore the cognitive processes used by professionals in understanding the item, explore any difficult word and comprehension of the items,
-
-

Introduction:

The respondents would be introduced about the study purpose, approximate time of engagement with FGD, and requirement of deeply exploring the comprehension of each item.

- I'm going to read the PHQ 9 Hindi items one by one.
- We will stop and discuss in detail about each question before moving onto the next.
- I will also ask you some more specific things about each question.
- I would also like to know any thoughts or views you might have about the questions.
- In case of any difference of opinion, feel free to refer to original PHQ 9 kept in the center of the group.

----- START INTERVIEW -----

Instruction: Read the item no.1 of PHQ 9 Hindi and discuss the following themes. Repeat the same set of questions for every item.

I. Comprehension:

- *What does the group believe the item to be asking?*
- Is there any difficult word in this item?
- Why does the word look difficult or what meaning does the word communicate to you?
- How would you like to replace the word?
- Any word you would like to add for better meaning?

II. Retrieval:

- *Is the time frame suitable to recall the information asked in the item?*

- Would there be a different time period that would be easier to understand?

III. Response:

- How would you define the response keys of this question/ your interpretation of the scoring keys?

- Is it appropriate to select an answer from the options given?

- Did all options make sense for this item?

IV. Other (to be asked at the end of all responses):

- Is there anything else you would like to say about any of the questions? / Questionnaire as a whole?

- Did you find any of the questions upsetting/ embarrassing / inappropriate?

----- THANKS -----

----- COMPLETION OF DEMOGRAPHICS CHART -----

Participants (experts') Characteristics

S.No.	Designation	Qualification	No. of years of experience
1			
2			
3			
4			
5			
6			
7			
8			
9.			
10.			

Appendix 2

Topic Guide to Interview Patient

Patient Health Questionnaire Pilot survey (Phase I)

Objective:

- To explore the cognitive processes used by respondents when reading, interpreting and responding to items on PHQ.

Introduction:

The respondents would be introduced about the study purpose, approximate time of engagement with interview (15 minutes), confidentiality, their right to stop any time and decline any questions

In this study I am less interested in your answers to the questions, but *how you arrive* at the answers – what you think the question means, and the things you were thinking about when you chose your answer. I would also like to know any thoughts or views you might have about the questions in **the last 2 weeks**.

----- START INTERVIEW -----

Q.1 रोज़मर्रा के कुछ काम करने में बहुत कम मन लगना

• Comprehension:

- What does the question mean to you, in your own words? (आपके लिए आपके अपने शब्दों में इस प्रश्न का क्या अर्थ है)
- Is there any difficult word to understand? How would you like to change this difficult word? (क्या कोई ऐसा शब्द है जिसे समझना मुश्किल है? आप इस कठिन शब्द को कैसे बदलना चाहेंगे?)
- How easy or difficult was *this question for you* to understand? (आपके लिए यह प्रश्न समझना कितना आसान या कठिन था)
- If this question is asked in other words as given below i.e. which version is easier for you to understand? (यदि यह प्रश्न दूसरे शब्दों में पूछा जाए, जैसा कि नीचे दिया गया है? -आपके लिए कौन सा संस्करण समझना आसान है?) (please tick the easier version for the respondent)

रोज़मर्रा के कुछ काम करने में बहुत कम मन लगना

कुछ करनेमें बहुत कमदिलचस्पी या मज़ा आना

• **Retrieval:**

- How well could you remember your experience when answering this question?(इस प्रश्न का उत्तर देते समय आप अपने अनुभव को कितनी अच्छी तरह याद कर सकें)
- Was it easy or difficult to think about the past two weeks when answering this question?(क्या इस प्रश्न का उत्तर देते समय पिछले दो सप्ताहों के बारे में सोचना आसान या कठिन था?)

• **Response:**

- Was it hard or easy to select an answer from the options given? (दिए गए विकल्पों में से उत्तर चुनना कठिन था या आसान?)
- Did all options make sense for this question?(क्या इस प्रश्न के लिए सभी विकल्प समझ में आए?)

Q.2 उदास, मन दुखी होना या निराश महसूस करना

• **Comprehension:**

- What does the question mean to you, in your own words? (आपके लिए आपके अपने शब्दों में इस प्रश्न का क्या अर्थ है)
- Is there any difficult word to understand? How would you like to change this difficult word? (क्या कोई ऐसा शब्द है जिसे समझना मुश्किल है? आप इस कठिन शब्द को कैसे बदलना चाहेंगे?)
- How easy or difficult was *this question for you* to understand? (आपके लिए यह प्रश्न समझना कितना आसान या कठिन था)
- If this question is asked in other words as given below i.e. which version is easier for you to understand? (यदि यह प्रश्न दूसरे शब्दों में पूछा जाए, जैसा कि नीचे दिया गया है? -आपके लिए कौन सा संस्करण समझना आसान है?) (please tick the easier version for the respondent)

उदास, मन दुखी होना या निराश महसूस करना	उदास, अवसादगर्स्त या निराश महसूस करना
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• **Retrieval:**

- How well could you remember your experience when answering this question?(इस प्रश्न का उत्तर देते समय आप अपने अनुभव को कितनी अच्छी तरह याद कर सकें)
- Was it easy or difficult to think about the past two weeks when answering this question?(क्या इस प्रश्न का उत्तर देते समय पिछले दो सप्ताहों के बारे में सोचना आसान या कठिन था?)

• **Response:**

- Was it hard or easy to select an answer from the options given? (दिए गए विकल्पों में से उत्तर चुनना कठिन था या आसान?)
- Did all options make sense for this question?(क्या इस प्रश्न के लिए सभी विकल्प समझ में आए?)

Q.3 नींद आने या सोये रहने में परेशानी, या फिर बहुत अधिक सोना

- **Comprehension:**

- What does the question mean to you, in your own words? (आपके लिए आपके अपने शब्दों में इस प्रश्न का क्या अर्थ है)
- Is there any difficult word to understand? How would you like to change this difficult word? (क्या कोई ऐसा शब्द है जिसे समझना मुश्किल है? आप इस कठिन शब्द को कैसे बदलना चाहेंगे?)
- How easy or difficult was *this question for you* to understand? (आपके लिए यह प्रश्न समझना कितना आसान या कठिन था)

- **Retrieval:**

- How well could you remember your experience when answering this question?(इस प्रश्न का उत्तर देते समय आप अपने अनुभव को कितनी अच्छी तरह याद कर सकें)
- Was it easy or difficult to think about the past two weeks when answering this question?(क्या इस प्रश्न का उत्तर देते समय पिछले दो सप्ताहों के बारे में सोचना आसान या कठिन था?)

- **Response:**

- Was it hard or easy to select an answer from the options given? (दिए गए विकल्पों में से उत्तर चुनना कठिन था या आसान?)
- Did all options make sense for this question?(क्या इस प्रश्न के लिए सभी विकल्प समझ में आए?)

Q.4 थकान महसूस करना या बहुत कमजोरी महसूस करना

- **Comprehension:**

- What does the question mean to you, in your own words? (आपके लिए आपके अपने शब्दों में इस प्रश्न का क्या अर्थ है)
- Is there any difficult word to understand? How would you like to change this difficult word? (क्या कोई ऐसा शब्द है जिसे समझना मुश्किल है? आप इस कठिन शब्द को कैसे बदलना चाहेंगे?)
- How easy or difficult was *this question for you* to understand? (आपके लिए यह प्रश्न समझना कितना आसान या कठिन था)
- If this question is asked in other words as given below i.e. which version is easier for you to understand? (यदि यह प्रश्न दूसरे शब्दों में पूछा जाए, जैसा कि नीचे दिया गया है? -आपके लिए कौन सा संस्करण समझना आसान है?) (please tick the easier version for the respondent)

थकान महसूस करना या बहुत कमजोरी महसूस करना	थकान महसूस करना या बहुत कमजोरी महसूस करना
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• **Retrieval:**

- How well could you remember your experience when answering this question?(इस प्रश्न का उत्तर देते समय आप अपने अनुभव को कितनी अच्छी तरह याद कर सकें)
- Was it easy or difficult to think about the past two weeks when answering this question?(क्या इस प्रश्न का उत्तर देते समय पिछले दो सप्ताहों के बारे में सोचना आसान या कठिन था?)

• **Response:**

- Was it hard or easy to select an answer from the options given? (दिए गए विकल्पों में से उत्तर चुनना कठिन था या आसान?)
- Did all options make sense for this question?(क्या इस प्रश्न के लिए सभी विकल्प समझ में आए?)

Q.5 भूख कम लगना या बहुत ज्यादा लगना

• **Comprehension:**

- What does the question mean to you, in your own words? (आपके लिए आपके अपने शब्दों में इस प्रश्न का क्या अर्थ है)
- Is there any difficult word to understand? How would you like to change this difficult word? (क्या कोई ऐसा शब्द है जिसे समझना मुश्किल है? आप इस कठिन शब्द को कैसे बदलना चाहेंगे?)
- How easy or difficult was *this question for you* to understand? (आपके लिए यह प्रश्न समझना कितना आसान या कठिन था)
- If this question is asked in other words as given below i.e. which version is easier for you to understand? (यदि यह प्रश्न दूसरे शब्दों में पूछा जाए, जैसा कि नीचे दिया गया है? -आपके लिए कौन सा संस्करण समझना आसान है?) (please tick the easier version for the respondent)

भूख कम लगना या बहुत ज्यादा लगना

भूख कम लगना या ज्यादा खाना

• **Retrieval:**

- How well could you remember your experience when answering this question?(इस प्रश्न का उत्तर देते समय आप अपने अनुभव को कितनी अच्छी तरह याद कर सकें)
- Was it easy or difficult to think about the past two weeks when answering this question?(क्या इस प्रश्न का उत्तर देते समय पिछले दो सप्ताहों के बारे में सोचना आसान या कठिन था?)

• **Response:**

- Was it hard or easy to select an answer from the options given? (दिए गए विकल्पों में से उत्तर चुनना कठिन था या आसान?)
- Did all options make sense for this question?(क्या इस प्रश्न के लिए सभी विकल्प समझ में आए?)

Q.6 अपने बारे में बुरा महसूस करना- या ऐसा महसूस करना कि आप सक्षम नहीं हैं और आपने खुद को और अपने परिवार को निराश किया है

- **Comprehension:**

- What does the question mean to you, in your own words? (आपके लिए आपके अपने शब्दों में इस प्रश्न का क्या अर्थ है)
- Is there any difficult word to understand? How would you like to change this difficult word? (क्या कोई ऐसा शब्द है जिसे समझना मुश्किल है? आप इस कठिन शब्द को कैसे बदलना चाहेंगे?)
- How easy or difficult was *this question for you* to understand? (आपके लिए यह प्रश्न समझना कितना आसान या कठिन था)
- If this question is asked in other words as given below i.e. which version is easier for you to understand? (यदि यह प्रश्न दूसरे शब्दों में पूछा जाए, जैसा कि नीचे दिया गया है? -आपके लिए कौन सा संस्करण समझना आसान है?) (please tick the easier version for the respondent)

अपने बारे में बुरा महसूस करना- या ऐसा महसूस करना कि आप सक्षम नहीं हैं और आपने खुद को और अपने परिवार को निराश किया है

अपने बारे में बुरा महसूस करना - या ऐसा महसूस करना कि आप नाकाम इंसान हैं और आपने खुद को और अपने परिवार को नीचा दिखाया है

- **Retrieval:**

- How well could you remember your experience when answering this question?(इस प्रश्न का उत्तर देते समय आप अपने अनुभव को कितनी अच्छी तरह याद कर सकें)
- Was it easy or difficult to think about the past two weeks when answering this question?(क्या इस प्रश्न का उत्तर देते समय पिछले दो सप्ताहों के बारे में सोचना आसान या कठिन था?)

- **Response:**

- Was it hard or easy to select an answer from the options given? (दिए गए विकल्पों में से उत्तर चुनना कठिन था या आसान?)
- Did all options make sense for this question?(क्या इस प्रश्न के लिए सभी विकल्प समझ में आए?)

Q.7 मनोरंजन के साधन जैसा अखबार पढ़ना, टीवी देखना, किताब पढ़ना, मोबाइल चलाना इत्यादि पर ध्यान देने में परशानी

- **Comprehension:**

- What does the question mean to you, in your own words? (आपके लिए आपके अपने शब्दों में इस प्रश्न का क्या अर्थ है)
- Is there any difficult word to understand? How would you like to change this difficult word? (क्या कोई ऐसा शब्द है जिसे समझना मुश्किल है? आप इस कठिन शब्द को कैसे बदलना चाहेंगे?)
- How easy or difficult was *this question for you* to understand? (आपके लिए यह प्रश्न समझना कितना आसान या कठिन था)

- If this question is asked in other words as given below i.e. which version is easier for you to understand? (यदि यह प्रश्न दूसरे शब्दों में पूछा जाए, जैसा कि नीचे दिया गया है? -आपके लिए कौन सा संस्करण समझना आसान है?) (please tick the easier version for the respondent)

मनोरंजन के साधन जैसा अखबार पढ़ना, टीवी देखना, किताब पढ़ना, मोबाइल चलाना इत्यादि पर ध्यान देने में परेशानी	अखबार पढ़ने या टेलीविजन देखने जैसी चीज पर ध्यान देने में परेशानी
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- **Retrieval:**

- How well could you remember your experience when answering this question?(इस प्रश्न का उत्तर देते समय आप अपने अनुभव को कितनी अच्छी तरह याद कर सकें)
- Was it easy or difficult to think about the past two weeks when answering this question?(क्या इस प्रश्न का उत्तर देते समय पिछले दो सप्ताहों के बारे में सोचना आसान या कठिन था?)

- **Response:**

- Was it hard or easy to select an answer from the options given? (दिए गए विकल्पों में से उत्तर चुनना कठिन था या आसान?)
- Did all options make sense for this question?(क्या इस प्रश्न के लिए सभी विकल्प समझ में आए?)

Q.8 कुछ काम को बहुत धीरे करना, धीरे चलना फिरना या धीरे बोलना या बहुत ज्यादा बेचैन रहना और सामान्य से बहुत ज्यादा चलते फिरते रहना

- **Comprehension:**

- What does the question mean to you, in your own words? (आपके लिए आपके अपने शब्दों में इस प्रश्न का क्या अर्थ है)
- Is there any difficult word to understand? How would you like to change this difficult word? (क्या कोई ऐसा शब्द है जिसे समझना मुश्किल है? आप इस कठिन शब्द को कैसे बदलना चाहेंगे?)
- How easy or difficult was *this question for you* to understand? (आपके लिए यह प्रश्न समझना कितना आसान या कठिन था)
- If this question is asked in other words as given below i.e. which version is easier for you to understand? (यदि यह प्रश्न दूसरे शब्दों में पूछा जाए, जैसा कि नीचे दिया गया है? -आपके लिए कौन सा संस्करण समझना आसान है?) (please tick the easier version for the respondent)

कुछ काम को बहुत धीरे करना, धीरे चलना फिरना या धीरे बोलना या बहुत ज्यादा बेचैन रहना और सामान्य से बहुत ज्यादा चलते फिरते रहना	इतना धीमे चलना- फिरना या बोलना कि लोगों का ध्यान जाए? या इसका उल्टा- इतना अस्थिर या बेचैन होना कि आप सामान्य से काफी ज्यादा हिलते डुलते और चलते- फिरते रहे
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- **Retrieval:**

- How well could you remember your experience when answering this question?(इस प्रश्न का उत्तर देते समय आप अपने अनुभव को कितनी अच्छी तरह याद कर सकें)

- Was it easy or difficult to think about the past two weeks when answering this question?(क्या इस प्रश्न का उत्तर देते समय पिछले दो सप्ताहों के बारे में सोचना आसान या कठिन था?)

- **Response:**

- Was it hard or easy to select an answer from the options given? (दिए गए विकल्पों में से उत्तर चुनना कठिन था या आसान?)

- Did all options make sense for this question?(क्या इस प्रश्न के लिए सभी विकल्प समझ में आए?)

Q.9 ऐसे विचार की आप मर जाए तो अच्छा होगा या किसी तरीके से खुद को नुक्सान पहुंचाना

- **Comprehension:**

- What does the question mean to you, in your own words? (आपके लिए आपके अपने शब्दों में इस प्रश्न का क्या अर्थ है)

- Is there any difficult word to understand? How would you like to change this difficult word? (क्या कोई ऐसा शब्द है जिसे समझना मुश्किल है? आप इस कठिन शब्द को कैसे बदलना चाहेंगे?)

- How easy or difficult was *this question for you* to understand? (आपके लिए यह प्रश्न समझना कितना आसान या कठिन था)

- If this question is asked in other words as given below i.e. which version is easier for you to understand? (यदि यह प्रश्न दूसरे शब्दों में पूछा जाए, जैसा कि नीचे दिया गया है? -आपके लिए कौन सा संस्करण समझना आसान है?) (please tick the easier version for the respondent)

ऐसे विचार की आप मर जाए तो अच्छा होगा या किसी तरीके से खुद को नुक्सान पहुंचाना	ऐसे विचार कि आप मर जाते तो अच्छा होता या किसी ढंग से खुद को नुक्सान पहुंचाना
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- **Retrieval:**

- How well could you remember your experience when answering this question?(इस प्रश्न का उत्तर देते समय आप अपने अनुभव को कितनी अच्छी तरह याद कर सकें)

- Was it easy or difficult to think about the past two weeks when answering this question?(क्या इस प्रश्न का उत्तर देते समय पिछले दो सप्ताहों के बारे में सोचना आसान या कठिन था?)

- **Response:**

- Was it hard or easy to select an answer from the options given? (दिए गए विकल्पों में से उत्तर चुनना कठिन था या आसान?)

- Did all options make sense for this question?(क्या इस प्रश्न के लिए सभी विकल्प समझ में आए?)

----- THANKS -----

----- COMPLETION OF DEMOGRAPHICS FORM -----

DEMOGRAPHIC SHEET

Name (optional):

Age:

Gender:

Education:

Occupation:

Cancer type:

How long back your disease was diagnosed:

Residence location:

----- THANKS -----

Appendix 3

रोगी स्वास्थ्य प्रश्नावली- 9 (PHQ-9)

मरीज़ का नाम:..... मरीज़ का कोड:..... दिनांक:.....

पिछले २ सप्ताहों में, आप इन समस्याओं में से किसी से भी कितनी बार परेशान रहे/रहीं हैं? (अपना उत्तर बताने के लिए “✓” का प्रयोग करें)	बिलकुल नहीं (0)	कुछ दिन (1)	आधे से अधिक दिन (2)	लगभग हर दिन (3)
1. रोज़ाना के कुछ काम करने में बहुत कम मन लगना				
2. उदास, मन दुखी होना या निराश महसूस करना				
3. नींद आने या सोये रहने में परेशानी, या फिर बहुत अधिक सोना				
4. थकान महसूस करना या बहुत कमजोरी महसूस करना				
5. भूख कम लगना या बहुत ज्यादा खाना				
6. अपने बारे में बुरा महसूस करना- या ऐसा महसूस करना कि आप असफल हैं और आपने खुद को और अपने परिवार को निराश किया है				
7. अखबार पढ़ना, टीवी देखना, किताब पढ़ना, मोबाइल चलाना जैसी चीज़ पर ध्यान देने में परेशानी				

8. इतना धीरे चलना फिरना, बोलना की लोगों का ध्यान जाए या इसका उल्टा जैसे बेचैन रहना या बहुत ज्यादा चलना फिरना				
9. ऐसे विचार की आप मर जाए तो अच्छा होगा या किसी तरह से खुद को नुक्सान पहुंचाना				

कुल गणना :

अगर आपने किसी समस्या पर निशान लगाया है तो बताएं कि इन समस्याओं ने आपके लिए काम करना, खुद का ध्यान रखना, घर पर चीजों की देखभाल करना, या दूसरे लोगों के साथ मेलजोल रखना कितना मुश्किल किया है ?

बिलकुल मुश्किल

थोड़ा-बहुत

बहुत

बेहद

नहीं

मुश्किल

मुश्किल

मुश्किल

Appendix 4

Comparison of PHQ 9 Original Hindi version versus current adapted version

Item No.	Original PHQ 9 Hindi	Adapted PHQ 9 Hindi
1	कुछ करने में बहुत कम दिलचस्पी या मज़ा आना	रोज़ाना के कुछ काम करने में बहुत कम मन लगना
2	उदास, अवसादग्रस्त या निराश महसूस करना	उदास, मन दुखी होना या निराश महसूस करना
3	नींद आने या सोये रहने में परेशानी, या फिर बहुत अधिक सोना	नींद आने या सोये रहने में परेशानी, या फिर बहुत अधिक सोना
4	थकान महसूस करना या बहुत कम ऊर्जा होना	थकान महसूस करना या बहुत कमजोरी महसूस करना
5	भूख कम लगना या ज्यादा खाना	भूख कम लगना या बहुत ज्यादा खाना
6	अपने बारे में बुरा महसूस करना - या ऐसा महसूस करना कि आप नाकाम इंसान हैं और आपने खुद को और अपने परिवार को नीचा दिखाया है	अपने बारे में बुरा महसूस करना- या ऐसा महसूस करना कि आप असफल हैं और आपने खुद को और अपने परिवार को निराश किया है
7	अखबार पढ़ने या टेलीविजन देखने जैसी चीज पर ध्यान देने में परेशानी	अखबार पढ़ना, टीवी देखना, किताब पढ़ना, मोबाइल चलाना जैसी चीज पर ध्यान देने में परेशानी
8	इतना धीमे चलना- फिरना या बोलना कि लोगों का ध्यान जाए? या इसका उल्टा- इतना अस्थिर या बेचैन होना कि आप सामान्य से काफी ज्यादा हिलते डुलते और चलते- फिरते रहे	इतना धीरे चलना फिरना, बोलना की लोगों का ध्यान जाए या इसका उल्टा जैसे बेचैन रहना या बहुत ज्यादा चलना फिरना
9	ऐसे विचार कि आप मर जाते तो अच्छा होता या किसी ढंग से खुद को नुकसान पहुंचाना	ऐसे विचार की आप मर जाए तो अच्छा होगा या किसी तरह से खुद को नुकसान पहुंचाना