

Extended Set on Functioning (ES-F)



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EXTENDED SET ON FUNCTIONING

The Extended set on functioning (ES-F) were developed based on the Washington Group extended Set on Functioning (WG-ES) which was developed, tested and adopted by the Washington Group on Disability Statistics (WG). Considering the country context and applicability, the Extended Set on Functioning was customized and is comprised of 26 questions in nine core functional domains: seeing, hearing, mobility (walking and climbing steps), cognition (remembering and concentrating), self-care, communication, upper body functioning, anxiety and depression and two additional domains: pain and fatigue.

The Extended Set on Functioning is intended for use among the adult population 18 years and above. Each domain is covered separately and the full set of questions is appended to the end of this document.

ADMINISTRATION OF THE QUESTIONS

The same four category response options are used for the domains of seeing, hearing, mobility (walking and concentrating), cognition (remembering and concentrating), self-care, communication and upper body functioning. For these domains, it is recommended that the response options be read aloud as part of each question as follows:

No, no difficulty Yes, some difficulty Yes, a lot of difficulty Cannot do it at all

Respondents may become familiar with the answer categories after the first few questions. In this case, the recommendation to repeat the categories can be relaxed. This is even more likely to occur when the questions are asked of multiple people in a household. If respondents provide responses using the required answer categories, the categories do not need to be repeated after every questions. They should be repeated as soon as the respondent does not use the required category (e.g., responds 'yes') or after the second or third question.

Different response options are used for the domains of affect, pain and fatigue. For questions that use a different set of answer categories, the response options should be read for the first administration of the question and thereafter as needed.

Enumerators will require training in when it is appropriate to not read the answer categories.

DOMAIN 1: SEEING

Do you wear glasses/Contact lenses? Yes/No

If Yes:

Do you have difficulty seeing, even if wearing glasses/Contact lenses?

If No:

Do you have difficulty seeing?

Domain:

The purpose of this domain is to identify persons with varying degrees of vision difficulties. Seeing difficulties include problems seeing things in day or night, close up or far away, reduced ability to see out of one or both eyes and limited peripheral vision.

Rationale: Seeing is measured with the use of corrective lenses if those lenses are used. This is determined through the first question: Do you wear glasses? "Glasses" includes all corrective lenses (including reading glasses) and contact lenses. Sunglasses should not be considered. "Glasses" are both ubiquitous and, when properly prescribed and used, often correct the difficulty completely, restoring normal vision. In this way, glasses are close to being 'within the skin' and are considered to be like corrective surgery in the way they affect functioning.

If the question were to ask about difficulty seeing without the use of glasses, the resultant prevalence would be extremely high and would not identify a population at risk of participation restriction.

For persons who do not wear glasses, the question just refers to seeing. For persons who report that they wear glasses, the question asks about difficulty seeing even when wearing glasses, which refers to seeing when the respondent has and uses glasses – NOT how vision would be if glasses, or better glasses, were provided to one who needed them.

The use of glasses that do not correct vision (difficulty seeing even if wearing glasses) would still be reported as a difficulty as would seeing problems where no glasses are worn.

DOMAIN 2: HEARING

Do you use a hearing aid?

If Yes:

Do you have difficulty hearing, even if using a hearing aid?

If No:

Do you have difficulty hearing?

Domain:

The purpose of the hearing domain is to identify persons who have hearing loss or auditory problems of any kind. This includes reduced hearing in one or both ears, or to distinguish sounds from different sources. Hearing refers to an individual using his/her ears and auditory (or hearing) capacity in order to know what is being said to them or the sounds of activity, including danger that is happening around them.

The question is intended to capture those who can hear the sounds but not those who do not understand or choose to ignore what is being said to them (i.e. the function of listening as opposed to hearing). Those concepts are captured in the communication domain.

Rationale: As was the case for seeing, hearing is evaluated with the use of hearing aids if these are worn. The use of hearing aids is not as ubiquitous as glasses/lenses, nor are they as successful in restoring hearing as glasses are for seeing.

When properly prescribed and used, however, they do aid in restoring normal hearing. In this way, hearing aids are close to being 'within the skin' and are considered to be like corrective surgery in the way they affect functioning.

If the question were to ask about difficulty hearing without the use of hearing aids, the resultant prevalence would be higher and would not identify a population at risk of participation restriction. For persons who do not use a hearing aid, the questions just refer to hearing. For persons who report using a hearing aid, the question asks about difficulty hearing even if using a hearing aid, which refers to hearing when the respondent has, and uses, that device – NOT how hearing would be if hearing aids, or better hearing aids, were provided to one who needed them.

The use of hearing aids that do not correct hearing (difficulty hearing even if using a hearing aid) would still be reported as a difficulty as would hearing problems where no hearing aids are worn. Included are problems hearing in any environment.

- Included are problems distinguishing sounds from different sources.
- Included are problems hearing in one ear or both ears.
- Any difficulty with hearing that is considered a problem should be captured.

DOMAIN 3: MOBILITY (WALKING AND/OR CLIMBING STEPS)

Do you have difficulty walking and/or climbing steps?

Do you use any equipment or receive help for getting around?

If Yes:

Do you use any of the following?

- A. Cane or walking stick
- B. Walker or zimmer frame
- C. Crutches
- D. Wheelchair or mobility scooter
- E. Artificial limb (leg/foot)
- F. Someone's assistance

Do you have difficulty walking 100 meters on level ground, that would be about the length of one archery ground[without the use of your aid]?

Do you have difficulty walking half a km on level ground, that would be the length of five archery ground [without the use of your aid]?

Do you have difficulty walking up or down 12 steps?

Do you have difficulty walking 100 meters on level ground, that would be about the length of one archery ground, when using your aid?

Do you have difficulty walking half a km on level ground, that would be the length of five archery ground, when using your aid?

Domain:

The purpose of this domain is to identify persons with varying degrees of difficulty walking and climbing steps. Both of these activities require a mix of strength, balance and the ability to control body movements against gravity. Walking is the primary mode used to move around and cover distances.

Difficulty walking is assessed both with and without the use of assistive devices if these are used: Do you use any equipment or receive help for getting around? The most common forms of walking aids are included: cane or walking stick, walker or zimmer frame, crutches, wheelchair or mobility scooter, prosthesis (artificial limb), or someone's assistance.

Rationale: If the person uses an assistive device, this series of questions captures their ability to

walk both with and without their equipment. Questions about walking without equipment capture a person's capacity to walk, while asking about walking with equipment, captures walking performance.

These questions differ from the seeing and hearing questions that measure the person's ability to function only with their assistive devices, if these are used. Mobility aids differ from seeing and hearing aids in two important ways. As noted in the section on seeing, glasses are more readily available and accessible than mobility aids in many countries due to their cost. They also are more successful in correcting the functional difficulty than are mobility devices in most contexts. In addition, while glasses and hearing aids are connected to the person (almost 'within-the-skin'), mobility aids vary widely. Aids such as canes improve walking ability, while wheelchairs provide a different means of getting from one place to another and therefore could be considered more of a substitute for walking.

The success with which mobility devices improve functioning in this domain is dependent on the environment where the person lives. The survey is interested in capturing the person's functionality with and without the assistance but cannot address how the device affects functioning in different environments. For example, a workplace may need a ramp for a person who uses a wheelchair. The wheelchair could improve the person's mobility but may not affect work participation if the work environment cannot accommodate the wheelchair.

Questions ask about difficulties in walking a short and a long distance. This specificity captures more variability in the ability to walk. A person with no difficulty walking a short distance but who is unable to walk longer distances may not be able to walk far enough to go to a bank or to vote. The question on the longer distance is more directly related to the ability to participate in society. By including both distance questions, the results provide a better differentiation in the population of the severity of walking difficulties experienced. While respondents may not have accurate knowledge of distances, the use of a common example for 100 meters (length of an archery ground) does give the respondent a good idea of the distance of interest. Asking about 100 meters first, followed by the question on 500 meters, gives an indicator of relative size that the respondent can use in forming an answer.

<u>Walking</u> refers to the use of lower limbs (legs) in such a way as to propel oneself over the ground to get from point A to point B. The capacity to walk should be without assistance of any device (wheelchair, crutches, walker etc.) or human. If such assistance is needed, the person has difficulty walking.

- Included are problems walking short (about 100 meters) or long distances (about 500 meters). For clarity 100 m could be explained with examples depending on the local environment.
- Difficulty walking any distance (100 meters) without stopping to rest is included.
- Difficulties walking can include those resulting from impairments in balance, endurance, or other non-musculoskeletal systems, for example, people who are blind or with severe loss of vision may have difficulty walking in an unfamiliar place.
- Included are problems walking up or down steps.
- Any difficulty with walking (whether it is on flat land or up or down steps) that is considered a problem should be captured.

DOMAIN 4: COGNITION (REMEMBERING AND CONCENTRATING)

Do you have difficulty remembering or concentrating?

Domain:

The purpose of this domain is to identify persons who have some problems with remembering or focusing attention that contribute to difficulty in doing their daily activities.

Remembering refers to the use of memory to recall incidents or events. It means the individual can bring to mind or think again about something that has taken place in the past (either the recent past or further back). With younger people, remembering is often associated with storing facts learned in school and being able to retrieve them when needed.

Remembering should NOT be equated with Memorizing or with good or bad memories.

Concentrating refers to the use of mental ability to accomplish some task such as reading, calculating numbers, learning something. It is associated with focusing on the task at hand in order to complete the task.

- Included are problems finding one's way around, being unable to concentrate on an activity, or forgetting one's whereabouts or the date.
- Included are problems remembering what someone just said.
- Any difficulty with remembering, concentrating or understanding what is going on around them that they or family members (if the family member is the respondent) consider a problem should be captured.
- Note: difficulties remembering or concentrating because of common everyday situations such as high workload or stress, or as a result of substance abuse are EXCLUDED.

Remembering and/or concentrating should be based on attention span. For example, if the primary caregiver is asked if the child could remember what meal he/she has taken, played with, their remembering as well as concentrating ability could be discerned.

DOMAIN 5: SELF-CARE

Do you have difficulty (with self-care such as) washing all over or dressing?

Domain:

The purpose of this domain is to identify persons who have some problems with taking care of themselves independently. The question specifies washing and dressing because these represent tasks that occur on a daily basis and are considered basic activities across cultures.

Washing all over refers to the process of cleaning one's entire body (usually with soap and water) in the usual manner for the culture.

The washing activity includes cleaning hair and feet, as well as gathering any necessary items for bathing such as soap or shampoo, a washcloth, or water.

Dressing refers to all aspects of putting clothing or garments on the upper and lower body including the feet if culturally appropriate.

- Included are the acts of gathering clothing from storage areas (i.e. closet, dressers), securing buttons, tying knots, zipping, etc.
- Includes the choice of clothing appropriate to the environment and climate.
- Washing and dressing represent tasks that occur on a daily basis and are considered basic, universal activities.

Difficulty in washing or dressing can occur because of a variety of functional difficulties including, but not limited to, difficulties in upper body functioning (e.g., use of arms, hands and fingers), lower body functioning, balance, cognitive functioning (e.g., choosing the appropriate clothes for the occasion and weather conditions) or psychosocial functioning.

Note: Distinguish between not willing to do and not able to do. Not willing to do does not mean an individual is not able to do, thus, he/she should not be considered as having difficulty in this domain.

DOMAIN 6: COMMUNICATION

Using your usual language, do you have difficulty communicating, (for example understanding or being understood by others)?

Do you have to communicate through assistive device/sign language?

Domain:

The purpose of this domain is to identify persons who have some problems with talking, listening or understanding speech such that it contributes to difficulty in making themselves understood to others or understanding others. Two aspects of communication that are measured through this question: understanding (receptive communication) and being understood (expressive communication).

Communicating refers to a person exchanging information or ideas with other people through the use of language.

The respondent's usual language is the means of communication that he/she normally uses. This is most often verbal, but may also be sign language or using assistive devices (i.e. computer-assisted communication and communication boards).

Communication difficulties can originate at numerous places in the exchange process. They may involve mechanical problems such as hearing impairment or speech impairment, or may be related to the ability of the mind to interpret the sounds that the auditory system is gathering and to recognize the words that are being used or an inability of the mind to compose a sentence or say a word even when the person knows the word and sentence.

- Included is the use of the voice for the exchange or using signs (including sign language) or writing the information to be conveyed.
- Included are problems making oneself understood or problems understanding other people when they speak or try to communicate in other ways.
- Hearing ability and communication are related but distinct domains. The degree and age of onset of hearing loss can affect communication differently.

Note: Difficulty understanding or being understood due to non-native or unfamiliar language is NOT included.

• If sign language is a person's usual language, he/she may have no difficulty communicating with others who also sign, but may experience a lot of difficulty or inability when communicating with those who do not sign. Respondents should report in terms of how they communicate most of the time (their usual language). The question on use of sign language will help to quantify these occurrences.

DOMAIN 7: UPPER BODY

Do you have difficulty raising a 2-liter bottle of water from waist to eye level?

Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?

Domain:

The purpose of this domain is to identify persons with difficulty in the coordination of arm/shoulder or hand/wrist muscle movements). 'Upper Body' is a concept that embraces a number of body structures and functions that include the shoulder, upper arm, lower arm, wrist or hand as well as back, and/or torso.

Upper body functioning requires two questions to adequately capture the full spectrum of activity in this domain. For this reason, it could not be included among the short set questions. While the short set self-care question, eliciting difficulty 'washing all over or dressing', will implicitly include many of those with difficulties in upper body functioning, many may not be identified with the self-care question. In addition, beyond upper body functioning, the self-care question will identify other, more complex difficulties associated with cognitive functioning, such as in choosing the appropriate clothes for the occasion and weather conditions.

The two Upper body questions focus on these activities: Raising a two-liter bottle of water captures aspects of the strength and coordination of arm and shoulder functioning and the ability of the hand/fingers to grip and hold. Picking up small objects/opening or closing containers captures the fine motors aspects of hand and finger coordination, dexterity, strength and movement.

DOMAIN 8: ANXIETY (AFFECT)

How often do you feel worried, nervous or anxious?

Do you take medication for these feelings?

Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?

DOMAIN 9: DEPRESSION (AFFECT)

How often do you feel depressed? Do you take medication for depression? Thinking about the last time you felt depressed, how depressed did you feel?

Affect is the domain of functioning dealing with emotional functions including feelings of depression and anxiety. These two domains are important to measure as they provide indications of psychosocial disability. Feelings of depression and anxiety are common occurrences in most people's lives. The answer categories allow for the identification of the most severe feelings of anxiety and depression.

The aim is to measure feelings of depression and anxiety that creates significant participation problems for individuals. Most people may at times have some worries and may feel sad, but when these feelings become both frequent and significant and result in restlessness, exhaustion, inattentiveness, irritability, tension, and sleep problems, they may interfere with the person's ability to interact and participate socially.

These questions are not meant to capture the response to a transitory event such as the anxiety associated with, for example, giving a presentation before colleagues and peers; or the normal grieving process such as one that accompanies the death of a family member.

Both anxiety and depression are measured on two dimensions: frequency and intensity; and the response categories are different from the previous domains of functioning.

How often one feels worried/nervous/anxious or depressed is a measure of frequency: never, some days, most days or every day.

The level of these feelings is a measure of the intensity of the anxiety/depression experienced: a little, a lot or somewhere in between a little and a lot.

In addition, for each aspect of psychosocial functioning (anxiety and depression) the use of medication specifically to deal with the feelings experienced is included. There is no specification regarding type of medication taken: over-the-counter or prescription; however, the purpose of including this question was to assess extent to which individuals 'treat' these feelings and determine if this has any impact on the results.

The short set did not include questions on psychosocial functioning since it was not possible to measure anxiety and depression using a single question, and this domain of functioning was considered inappropriate in a census setting.

The domain of affect is similar to that of cognition where there is a continuum from full functioning to full disability and a meaningful cutoff point needs to be found to separate what is considered to be significant difficulty (and counted as being 'in scope') from common feelings that are less severe and more transient in nature ('out of scope').

DOMAIN 10: PAIN

In the past 3 months, how often did you have pain?

Thinking about the last time you had pain, how much pain did you have?

While most of the questions included in the Short set and Extended set fall discretely into a core domain of functioning, such as physical, sensory, psychological or cognitive functioning, pain does not. Pain is not a domain of functioning, nor is it confined to a single or specific domain of functioning. It is a symptom, rather than a specific health diagnosis or disease, and can be related to any of the aforementioned domains.

Pain is multi-dimensional and is measured on two axes: frequency and intensity. How often one experiences pain is a measure of frequency: never, some days, most days or every day. How much pain was experienced is a measure of the intensity of the pain: a little, a lot or somewhere in between a little and a lot.

Though pain is a symptom rather than a domain of basic functioning (such as seeing, hearing, walking or remembering), it is one which can strongly influence those actions and can be more prominent in the respondent's mind as the relevant cause of the problems with basic actions. For example, when asked about walking or standing the respondent who experiences pain may highlight that fact rather than any difficulty actually walking or standing. As such, pain becomes an important mediating factor in understanding difficulties in other domains of functioning. Of interest is to determine whether people report both difficulties with pain as well as its impact on other domains (e.g. difficulty walking or remembering and concentrating) or only the pain and not its impact on these other domains.

DOMAIN 11: FATIGUE

In the past 3 months, how often did you feel very tired or exhausted?

Thinking about the last time you felt very tired or exhausted, how long did it last?

Thinking about the last time you felt this way, how would you describe the level of tiredness?

Fatigue, in the context of the extended set, is considered temporary or extended weariness or exhaustion that manifests itself physically, mentally ("sem thangchey"), or through the senses or any combination of those.

Fatigue is multi-dimensional and is measured on three axes: frequency, intensity and duration. How often one feels fatigue is a measure of frequency: never, some days, most days or every day. How long the feeling of fatigue lasted is a measure of the duration of fatigue: some of the day, most of the day or all of the day.

The level of fatigue is a measure of the intensity of the fatigue experienced: a little, a lot or somewhere in between a little and a lot.

Though fatigue is a symptom rather than a domain of basic functioning (such as seeing, hearing, walking or remembering), it is one which can strongly influence those actions and, like pain, can be more prominent in the respondent's mind as the relevant cause of the problems with basic actions. For example, when asked about walking or standing the respondent who experiences fatigue may highlight that fact rather than any difficulty actually walking or standing. As such, fatigue becomes an important mediating factor in understanding difficulties in other domains of functioning. Of interest is to determine whether people report both difficulties with fatigue as well as its impact on other domains (e.g. difficulty walking or remembering and concentrating) or only the fatigue and not its impact on these other domains.

ANNEXURE: EXTENDED SET QUESTIONNAIRE

18 YEARS AND ABOVE DOMAN 1: SEEING

1	Do you wear glasses or contact lenses ?	
	Yes (>>1b)	1
	No	2
1a	Do you have difficulty seeing?	
	No difficulty	1
	Some difficulty	2
	A lot of difficulty	3
	Cannot do at all	4
	>>2	
1b	Do you have difficulty seeing even if wearing glasses or contact lenses?	
	No difficulty	1
	Some difficulty	2
	A lot of difficulty	3
	Cannot do at all	4
DOMA	IN 2: HEARING	
2	Do you use hearing aid?	
	Yes(>>2b)	1
	No	2
2a	Do you have difficulty hearing?	
	No difficulty	1
	Some difficulty	2
	A lot of difficulty	3
	Cannot do at all	4
	>>3	
2b	Do you have difficulty hearing even if using hearng aid?	
	No difficulty	1
	Some difficulty	2
	A lot of difficulty	3
	Cannot do at all	4

DOMAIN 3: MOBILITY

3	Do you have difficulty walking or climbing steps?	
	No difficulty	1
	Some difficulty	2
	A lot of difficulty	3
	Cannot do at all	4
3a	Does (name) use any equipment or receive assistance for walking?	
	Yes	1
	No(>>5)	2
4		
4	Do you use any of the following?(mark all that apply)	1
	Cane or walking stick	1
	Walker or Zimmer frame	2
	Crutches	3
	Wheelchair or mobility scooter? (skip to cognition section)	4
	Artificial limb (leg/foot)	5
	Someone's assistance	6
5	Do you have difficulty walking 100 meters on level ground, that would be about the length of one archery ground [without the use of your aid if q3a==1]?	
	No difficulty	1
	Some difficulty	2
	A lot of difficulty	3
	Cannot do at all (skip to q7)	4
6	Do you have difficulty walking half a km on level ground, that would be the length of five archery ground [without the use of your aid if q3a==1]?	
	No difficulty	1
	Some difficulty	2
	A lot of difficulty	3
	Cannot do at all	4

7	Do you have difficulty walking up or down 12 steps? No difficulty Some difficulty A lot of difficulty Cannot do at all If 3a= 2 "No", skip to cognition section. Q4 = 4 "Wheelchair", skip to cognition	1 2 3 4
	section	
8	Do you have difficulty walking 100 meters on level ground, that would be about the length of one archery ground [with the use of your aid]? No difficulty Some difficulty A lot of difficulty Cannot do at all(Skip to q10)	1 2 3 4
9	Do you have difficulty walking half a km on level ground, that would be the length of five archery ground [with the use of your aid]? No difficulty Some difficulty A lot of difficulty Cannot do at all	1 2 3 4
	IN 4: COGNITION	
10	Do you have difficulty remembering or concentrating? No difficulty Some difficulty A lot of difficulty Cannot do at all	1 2 3 4
DOMA	IN 5: SELF CARE	
11	Do you have difficulty (with self-care such as) washing all over or dressing? No difficulty Some difficulty A lot of difficulty Cannot do at all (note: Not willing to do is different from not able to do)	1 2 3 4

DOMAIN 6: COMMUNICATION

12	Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?	
	No difficulty	1
	Some difficulty	2
	A lot of difficulty	3
	Cannot do at all	4

Oo you have to communicate through assistive device/sign language?	
ign language	1
Computer-assisted communication	2
Communication boards	3
Others	96
lo	4
j)	ign language omputer-assisted communication ommunication boards others

DOMAIN 7: UPPER BODY

14	Do you have difficulty raising a 2 liter bottle of water from waist to eye level?	
	No difficulty	1
	Some difficulty	2
	A lot of difficulty	3
	Cannot do at all	4

15	Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?	
	No difficulty	1
	Some difficulty	2
	A lot of difficulty	3
	Cannot do at all	4

DOMAIN 8: ANXIETY

How often do you feel worried, nervous or anxious?		
Daily	1	
Weekly	2	
Monthly	3	
A few times a year	4	
Never	5	
	Daily Weekly Monthly A few times a year	

17	Do you take medication for these feelings?	
	Yes	1
	No (If "Never" in 16 and "No" in 17, skip to 19)	2
18	Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?	
	A little	1
	A lot	2
	Somewhere in between a little and a lot	3

DOMAIN 9: DEPRESSION

19	How often do you feel depressed?	
	Daily	1
	Weekly	2
	Monthly	3
	A few times a year	4
	Never	5
20	Do you take medication for depression?	
	Yes	1

No (If "Never" in 19 and "No" in 20, skip to 22)
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21	Thinking about the last time you felt depressed, how depressed did you feel?	
	A little	1
	A lot	2
	Somewhere in between a little and a lot	3

DOMAIN 10: PAIN

22

	Never (If "Never" skip to 24)	1
	Some days	2
	Most days	3
	Every day	4
23	Thinking about the last time you had pain, how much pain did you have?	
	A little	1
	A lot	2
	Somewhere in between a little and a lot	3

DOMAIN 11: FATIGUE

In the I	past 3 months, l	how often c	did you feel	very tired or	exhausted?
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In the past 3 months, how often did you have pain?

Never (If "Never" end)	1
Some days	2
Most days	3
Every day	4

25	Thinking about the last time you felt very tired or exhausted, how long did it last?	
	Some of the day	1
	Most of the day	2
	All of the day	3

26 Thinking about the last time you felt this way, how would you describe the level of tiredness?

A little	1
A lot	2
Somewhere in between a little and a lot	3



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