

The Washington Group Extended Set on Functioning: Question Specifications

Introduction

The Washington Group Extended Set on Functioning (WG-ES) is intended for use in population-based health surveys, as well as surveys that focus specifically on disability. The WG-ES was developed, tested and adopted by the Washington Group on Disability Statistics (WG).

This document provides a description of each of the questions in the WG Short Set on Functioning (WG-SS). Information on the intent of the question, the concepts being measured, and the purpose of the specific language used is presented in order to improve understanding for translation and administration of the questions, as well as analysis of the resulting data.

The specifications have the dual purpose of aiding the translator in preparing a translation into the local language(s) and the interviewer in preparing for fieldwork and data collection. Question specifications explain to the translator and interviewer the purpose of the question, why particular wording is used, and describes in detail the main concepts that are being measured.

The WG Extended Set Questions

The Washington Group Extended Set on Functioning is intended for use among the adult population 18 years of age or above. The module comprises about 35 questions (depending on skip patterns) in eleven core functional domains: seeing, hearing, mobility (walking and climbing steps), cognition (remembering and concentrating), self-care, communication, upper body functioning, anxiety, depression, pain and fatigue.

Domains are intended to measure non-accommodated

The <u>Washington Group</u> <u>Implementation Documents</u>

cover the tools developed by the Washington Group on Disability Statistics (WG) to collect internationally comparable disability data on censuses and surveys. The documents address best practices in implementing the Short Set, Extended Set, Short Set – Enhanced, the WG / **UNICEF Child Functioning** Modules for children 2-4 and 5-17 years of age, and the WG / ILO LFS Disability Module, as well as other WG tools. Topics include translation, question specifications, analytic guidelines, programming code for analyses, the use of the tools for the purposes of disaggregation, and more.

To locate other WG Implementation Documents and more information, visit the Washington Group website: <u>http://www.washingtongroupdisability.com/</u>.

functioning with the exception of the seeing and hearing domains [see below]. The mobility domain includes both **accommodated** and **non-accommodated** functioning.

Apart from questions on pain and fatigue, no time frame (e.g., During the past 6 months) is referenced in the questions. Cognitive testing of the questions has provided evidence that making reference to a time period confuses respondents unnecessarily and that even if a time frame is specified the response often does not relate to that time frame. In the absence of a timeframe, respondents will generally recall their current state. The WG website contains a blog that addresses this issue: *Should the Washington Group Questions Determine if Difficulties are Long-term or Short-term?*

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. The response categories are read after each question, and capture the full spectrum of functioning from mild to severe.

- 1. No, no difficulty
- 2. Yes, some difficulty
- 3. Yes, a lot of difficulty
- 4. Cannot do it at all

It is recommended that the response options be read aloud as part of each question as follows:

"Do you have difficulty walking or climbing steps? Would you say: No, no difficulty, Yes, some difficulty, Yes, a lot of difficulty, or 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 most 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. Enumerators will require training in when it is appropriate to not read the answer categories.

Responses to the Washington Group questions attempt to describe a continuum of functioning and response categories were selected to evenly distribute responses along a continuum. 'No difficulty' and 'cannot do at all' are the extremes of the distribution, anchoring its endpoints, and are clear concepts that are unambiguous and straightforward. 'Some difficulty' and 'a lot of difficulty' are less definitive. For example, 'some' and 'a lot' should not be understood or interpreted as 'moderate' and 'severe' respectively. The result of such an interpretation would skew the distribution towards the 'cannot do at all' end of the continuum and would miss many of those at risk if the recommended cut-off of 'a lot of difficulty' was utilized. The words 'some' and 'a lot' were selected to divide the continuum into three relatively equal parts.



For more information on the Washington Group on Disability Statistics, visit: http://www.washingtongroup-disability.com/.

The distribution above creates four points equally distributed among the continuum that allows respondents to more easily discriminate among options. The recommended cut-off correctly identifies those with the intended level of difficulties. The translation of 'some' and 'a lot' should identify the population with the same functional status as that identified by the cognitively tested English version. Whether this has been successful can be determined by cognitively testing the translated questions.

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 question. 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 affect domain – anxiety and depression. 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.

Question Specifications

Introductory Statement: The next questions ask about difficulties you may have doing certain activities because of a health problem.

The purpose of the introduction is to transition from questions in the census or survey that deal with other subject matter to a new area of inquiry, and focus the respondent on difficulties they may have that relate to physical or mental health. Use of the introductory statement may not be needed in all situations, especially if including the statement may interrupt the flow of question administration.

It is also possible to change the wording of the introduction, as needed, as long as the word 'disability' is not used. Alternative recommendations include:

- The next questions ask about difficulties you may have in doing certain activities.
- Now I am going to ask you some questions about your ability to do different activities.

For more information, see the Washington Group FAQ on this subject at: <u>http://www.washingtongroup-disability.com</u>

<u>Difficulties</u> include those experienced within a health context, *not* those caused by a lack of resources.

<u>Health</u> refers to the general condition of the body or mind with reference to soundness, vitality, and freedom from disease.

Introductory Statement, continued:

<u>Problem</u> refers to the respondent's perception of a departure from physical, mental or emotional well-being. This includes specific health problems such as a disease or chronic condition, a missing limb or organ or any type of impairment or physical or psychological symptoms.

It also includes more vague disorders not always thought of as health-related such as senility, depression, developmental delay or intellectual impairment, drug dependency, accidental injuries, etc.

Seeing:

1. Do you wear glasses? Yes/No

If Yes: 2a. Do you have difficulty seeing, even if wearing glasses?

If No: 2b. Do you have difficulty seeing?

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.

<u>Seeing</u> is measured with the use of corrective lenses if those lenses are used. This is a measure of accommodated functioning. Whether corrective lenses are used is determined through the first question: Do you wear glasses? "Glasses" includes all corrective lenses (including reading glasses) and contact lenses. "Glasses" are both ubiquitous and in most cases are readily available and pervasive. When properly prescribed and used corrective lenses often correct the difficulty completely, restoring normal vision. In this way, corrective lenses are close to being 'within the skin' and are considered to be like corrective surgery in the way they improve 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.

The question Do you wear glasses? sets up a skip pattern. For persons who do not wear glasses, the following question just refers to seeing without mention of glasses. 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 (i.e., difficulty seeing even if wearing glasses) would still be reported as a difficulty as would seeing problems where no glasses are worn.

Hearing:

3. Do you use a hearing aid?

If Yes: 4a. Do you have difficulty hearing, even if using a hearing aid?

If No: 4b. Do you have difficulty hearing?

5. Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [even when using your hearing aid(s)]?

6. Do you have difficulty hearing what is said in a conversation with one other person in a noisier room [even when using your hearing aid(s)]?

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.

<u>Hearing</u> 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. Difficulty hearing includes:

- problems hearing in any environment.
- problems distinguishing sounds from different sources.
- problems hearing in one ear or both ears.
- any difficulty with hearing that is considered a problem.

The question is not intended to capture those who can hear the sounds but either 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.

As was the case for seeing, hearing is evaluated with the use of hearing aids if these are worn. This is a measure of accommodated functioning. Whether hearing aids are used is determined through the first question: Do you use a hearing aid? 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 improve 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.

Hearing, continued:

The question Do you use a hearing aid? sets up a skip pattern. For persons who do not use a hearing aid, the following questions just refer to hearing without mention of hearing aids. 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 (i.e., difficulty hearing even if using a hearing aid) would still be reported as a difficulty as would hearing problems where no hearing aids worn.

Two additional questions on hearing are asked to obtain additional information on the level of difficulty in hearing. The first refers to difficulty hearing what is said in a conversation with one other person in a quiet room (easier activity) and the second, difficulty hearing what is said in a conversation with one other person in a nosier room (more difficult activity). Having difficulty hearing in a quiet environment indicates that the extent of the hearing problem is likely to be moderate to severe and have a bigger impact on participation. Many more people are likely to find hearing in a noisier environment difficult. Each of these questions includes the hearing aid clause if the respondent has reported using such a device in the first question.

Mobility (Walking and Climbing Steps):

7. Do you have difficulty walking or climbing steps?

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

If Yes:

- 9. Do you use any of the following?
 - a. Cane or walking stick?
 - b. Walker or Zimmer frame?
 - c. Crutches?
 - d. Wheelchair or scooter?
 - e. Artificial limb (leg/foot)?
 - f. Someone's assistance?

10. Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [without the use of your aid]?

11. Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks [without the use of your aid]?

12. Do you have difficulty walking up or down 12 steps?

13. Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block, when using your aid?

14. Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks, when using your aid?

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.

<u>Walking</u> refers to the use of lower limbs (legs) in such a way as to propel oneself over the ground in an upright position to get from point A to point B. Similarly, <u>climbing steps</u> refers to the use of lower limbs (legs) in such a way as to ascend a set of stairs or a ladder. The capacity to walk or climb steps [Question 1] should be without assistance of any device (wheelchair, crutches, walker etc.) or from a person. If such assistance is needed, the person has difficulty walking.

- Difficulty walking any distance 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.

Difficulty walking is further assessed both with and without the use of assistive devices if these are used. This is determined through the question: Do you use any equipment or receive help for getting around? If the answer is Yes, the most common forms of walking aids are included in a list to be checked by the respondent: cane or walking stick, walker or Zimmer frame, crutches, wheelchair or scooter, prosthesis (artificial limb), or someone's assistance.

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

Mobility, continued:

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/yards (length of a football field) does give the respondent a good idea of the distance of interest. Asking about 100 meters/ yards first, followed by the question on 500 meters/ yards, gives an indicator of relative size that the respondent can use in forming an answer. It is however recommended that country specific examples are used to facilitate greater understanding of the actual distance.

Cognition (Remembering and Concentrating):

15. Do you have difficulty remembering or concentrating?

16. Do you have difficulty remembering, concentrating, or both?

17. How often do you have difficulty remembering?

- 1. Sometimes
- 2. Often
- 3. All of the time

18. Do you have difficulty remembering a few things, a lot of things, or almost everything?

NOTE: Answer categories for some of these questions differ from earlier domains. These are included in the specifications below.

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.

Cognition, continued:

<u>Remembering</u> 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.

<u>Concentrating</u> 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.

Four questions capture the breadth of cognitive functioning. The first question replicates the WG-SS cognitive functioning question and elicits difficulty in either aspect of cognition: remembering **or** concentrating. Question #2 differentiates between these two aspects and asks whether one, the other or both are implicated. Questions #3and #4 begin to delve into the severity of cognitive difficulty by asking about the frequency [How often...] and scope [a few things, a lot of things, or almost everything] of difficulty remembering.

Self-Care:

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

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.

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

Self-Care, continued:

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.

<u>Dressing</u> 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.

Communication:

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

21. Do you use sign language?

The purpose of this domain is to identify persons who have 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).

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

The respondent's <u>usual language</u> 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

Communication, continued:

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.

A second question is included on the use of sign language: Do you use sign language? Like spoken language, sign language varies from country to country. The use of sign language refers to that used by people with hearing difficulties to communicate with others where they live/in their communities.

• 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 understand the mechanism through with the communication occurs.

Upper Body:

22. Do you have difficulty raising a 2 liter bottle of water or soda from waist to eye level?

23. 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?

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 WG-SS questions. While the WG-SS 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

Upper Body, continued:

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 from waist to eye level captures aspects of the strength and coordination of arm and shoulder functioning and the ability of the hand/fingers to grip and hold. A two liter bottle was chosen after considerable testing in several countries/languages. It was found to an object that was common universally.

Picking up small objects or opening or closing containers captures the fine motor aspects of hand and finger coordination, dexterity, strength and movement.

Affect – Anxiety and Depression:

24. How often do you feel worried, nervous or anxious?

- 1. Daily
- 2. Weekly
- 3. Monthly
- 4. A few times a year
- 5. Never

25. Do you take medication for these feelings?

- 1. Yes
- 2. No

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

- 1. A little
- 2. A lot
- 3. Somewhere in between a little and a lot
- 27. How often do you feel depressed?
 - 1. Daily
 - 2. Weekly
 - 3. Monthly
 - 4. A few times a year
 - 5. Never

28. Do you take medication for depression?

- 1. Yes
- 2. No

29. Thinking about the last time you felt depressed, how depressed did you feel?

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

NOTE: Answer categories for these questions differ from earlier domains. These are included in the specifications below.

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.

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 even 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 <u>frequency along a</u> <u>continuum from</u> never having those feelings, to some days, most days or every day at the other end of the spectrum.

The **level of these feelings** is a measure of the <u>intensity</u> of the anxiety/depression experienced also described along a continuum ranging from a little to a lot, or somewhere in between a little and a lot. The question on level of feelings refers to 'the last time' the respondent had those feeling. The question focuses on the most recent occurrence because intensity can vary across occurrences and this standardizes the reference for all respondents.

These two dimensions are combined to describe a continuum of functioning in these domains.

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, e.g., 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. There is no instruction as to whether the intensity is to be reported with

Affect, continued:

medication or without. This is left to the respondent, and in most, cases reporting will be 'with medication'.

The WG-SS did not include questions on psychosocial functioning since it was not possible to measure anxiety and depression using a single question (a WG-SS requirement), and this domain of functioning was considered inappropriate in a census setting (also an early WG requirement for the WG-SS).

Pain:

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

- 1. Never
- 2. Some days
- 3. Most days
- 4. Every day

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

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

NOTE: Answer categories for these questions differ from earlier domains. These are included in the specifications below.

While most of the questions included in the WG-SS and WG-ES 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 as a domain in the WG-ES is not limited to the physical experience of pain, but also include aspects of mental or psychosocial pain. Pain can also be associated with 'anguish' related to distress or anxiety.

Pain is multi-dimensional and is measured on two axes: frequency and intensity.

How often one experiences pain is a measure of <u>frequency along a continuum from</u> never experiencing pain, to some days, most days or every day at the other end of the spectrum. Because the experience of pain can be more variable than other domains, and can be related to past traumatic experiences, respondents are asked to consider a time period of the past three months when considering episodes of pain.

Pain, continued:

How much pain was experienced is a measure of the <u>intensity</u> of the pain also described along a continuum ranging from a little to a lot, or somewhere in between a little and a lot. For those who responded that they had experienced pain in the previous question, and because frequency is measured from every day to some days, the measure of intensity is referenced to 'the last time' the respondent had those feelings in order that they focus on the most recent occurrence. The question on level of pain refers to 'the last time' the respondent experienced pain. The question focuses on the most recent occurrence because intensity can vary across occurrences and this standardizes the reference for all respondents.

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.

Fatigue:

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

- 1. Never
- 2. Some days
- 3. Most days
- 4. Every day

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

- 1. Some of the day
- 2. Most of the day
- 4. All of the day

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

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

NOTE: Answer categories for these questions differ from earlier domains. These are included in the specifications below.

Fatigue, in the context of the WG-ES, is considered temporary or extended weariness or exhaustion that manifests itself physically, mentally, 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 <u>frequency along a continuum from</u> never experiencing fatigue, to some days, most days or every day at the other end of the spectrum. Because the experience of fatigue, like pain, can be more variable than other domains, respondents are asked to consider a time period of the past three months when considering episodes of fatigue.

For those who experienced fatigue at least some days in the question above, the duration of that fatigue is measured by asking **How long** the feeling of fatigue lasted. The duration of fatigue is a measure along a continuum from some of the day, through most of the day to all of the day at the extreme end of the spectrum.

The **level of fatigue** is a measure of the <u>intensity</u> of the fatigue experienced also described along a continuum ranging from a little to a lot, or somewhere in between a little and a lot.

The question on level of fatigue refers to 'the last time' the respondent experienced fatigue. The question focuses on the most recent occurrence because intensity can vary across occurrences and this standardizes the reference for all respondents.

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, like pain, becomes an important mediating factor in understanding difficulties in other domains of functioning.