ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
MODIFIED DYSPNEA INDEX

Form Completion Instructions:

See detailed instructions below on how to complete the Modified Dyspnea Index. In should be done by the same interviewer from visit to visit for a patient. If should be done each time without having previous results available.

The score on each of the four components will be combined into a total Modified Dyspnea Index score which will be calculated at the Clinical Coordinating Center for future analysis.

CODING INSTRUCTIONS FOR COMPLETING THE DYSPNEA INDEX BASED ON A PATIENT INTERVIEW

I. BASIC INSTRUCTIONS

This scale is used to measure the patient's shortness of breath and its impact on his/her activities. The scale consists of three basic categories: 1) "functional impairment", which is a measure of the degree to which the patient's activities have been impaired by shortness of breath, 2) "magnitude of task", a measure of the amount of effort the patient must use in order to perform his/her most strenuous task. We request that you ask the patient detailed questions about these three aspects of his/her disease and then enter your "grade" for the patient in each of the three categories just mentioned. Please notice several things:

(1) The "functional impairment" scale assesses the patient's performance both at work (if employed and in his/her home duties (like shopping, cleaning, making the bed, working in the garden, etc.). Entering in the patient's grade for "functional impairment", then, requires that you inquire about that activities the patient does during an average day and whether they have changed at all as a result of his/her shortness of breath. For specific guidelines about entering the grade in any of the three categories, please refer to the coding instructions that follow these basic instructions.

(2) This scale is intended to measure shortness of breath. If the patient has another illness or disability (besides shortness of breath) which is the main cause of his/her limitations, we wish to know this. If the patient has another limiting disability besides shortness of breath, we ask that you enter only grade Y ("impaired for reasons other than shortness of breath") for the appropriate category.

(3) If the patient cannot specify his/her degree of impairment in any of the categories, please enter grade W ("amount uncertain") for that category.

II. FUNCTIONAL IMPAIRMENT AT WORK: Instructions To The Interviewer

In this section, we ask you to evaluate what effect the patient's shortness of breath has had on his/her work experience. To do this accurately, please ask the patient several specific questions and assign a grade to the patient based on the criteria that categorize the answers to these questions. It will be important to find out answers to the following:

(1) Does the patient have any noticeable shortness of breath under any circumstances?

(2) Was the patient employed at the time shortness of breath began?

(3) If the patient was not working when his/her shortness of breath was first noticeable, has (s)he since tried to find work and, if so, did the dyspnea determine the kind of job (s)he could perform?

(4) If the patient does have dyspnea and was working when the symptom began, did the shortness of breath cause him/her to curtail or in any way change the work activities (s)he could perform?

(5) If so, exactly how?

(6) Please notice that a separate axis follows in which you are asked to assess the patient's functional impairment at home. Activities which are exclusively related to being a "housespouse" are to be assessed in that axis, leaving work impairment to apply to more formal "jobs". Assign grade Z to the non-breadwinner who has not worked since before shortness of breath began.

Based on the patient's answers to your careful inquiry about these issues and your reading of the coding criteria that follow, you should be able to assign a grade for the patient's "functional impairment at work".

III. CRITERIA FOR GRADE ASSIGNMENT: Functional Impairment at Work

_____ **Grade 4:** **No Impairment**. The patient is able to carry out usual job-related activities without shortness of breath. To be classified as grade 4, the patient should:

(a) Not have changed jobs or job activities as a result of shortness of breath.

(b) Not, for reasons of shortness of breath have

(a) Decreased the amount of hours/week (s)he works, or

(b) Curtailed any job-related activities because they were too strenuous, either by eliminating certain tasks in the same job or by changing jobs to a less physically demanding one.

_____ **Grade 3:** **Slight Impairment**. The patient recognizes that shortness of breath has caused him/her to alter job activities, namely:

(a) Although no job responsibilities have been completely abandoned as a result of shortness of breath, at least one job related task is done more slowly due to shortness of breath.

_____ **Grade 2:** **Moderate Impairment**. The patient has:

(a) Maintained the same job and same hours/week as before the onset of dyspnea but, because of shortness of breath, has abandoned completely at least one of the tasks (s)he had done as part of that job, or

(b) Changed jobs to a less strenuous position, because shortness of breath interfered with job activities, or

(c) Maintained his/her pre-morbid job (e.g., the job (s)he had before dyspnea began), but decreased the number of hours/week work at that job.

Notably (b) and (c) are not mutually exclusive, as when the patient decreases the amount of hours on one job but adds a second, less strenuous one to make ends meet. This situation is also coded as grade 2.

_____ **Grade 1:** **Severe Impairment**. The patient no longer works because of shortness of breath. This would include:

(a) Patients who have retired early from their job because of shortness of breath and who, despite a desire to work, have not found a realistically limited job because of shortness of breath.

Patients who reached expected retirement age and stopped working and who also have dyspnea are graded according to how their shortness of breath affected their job before retiring.

Example: The construction worker who left the work to take a desk job because of shortness of breath and who, having reached retirement age, is now no longer working, would be assigned grade 2 for "functional impairment at work" rather than grade 1.

_____ **W:** **Amount Uncertain**. Patient is impaired due to shortness of breath, but amount cannot be specified. Details are not sufficient to allow impairment to be categorized.

_____ **X:** **Unknown**. Information unavailable regarding impairment.

_____ **Y:** **Impaired for Reasons Other than Shortness of Breath**. Grade Y is assigned if the patient has a limitation in job activities (or stopped working) and the main cause of this limitation is a disability other than shortness of breath as, for example, hip disease or some other musculoskeletal impairment, or chest pain.

Please describe the nature of the other limiting condition(s):

_____

_____

_____ **Z:** The patient has not had a job since before symptoms of shortness of breath began and has not since sought work.

Example: the non-breadwinner who had not intended to find a job even before shortness of breath began.

For patients who were not working when their shortness of breath began but who have since begun to work and for whom shortness of breath was a factor in determining their job, code as grade 2.

IV. FUNCTIONAL IMPAIRMENT AT HOME: Instructions To The Interviewer

In the section, we ask you to evaluate whether the patient's shortness of breath has impaired his/her home and/or recreational activities. The term "usual activities" used here refers to those activities of daily living and home responsibility that the patient would, or used to, habitually perform when in a state of pulmonary health (i.e., without impairment by dyspnea). Examples include activities of self-care (e.g., washing, eating), shopping, upkeep and cleaning of the residence and recreational activities both around the house (e.g., gardening, maintenance) and out of the house (e.g., playing sports, watching sports live, movie and theater-going, etc.).

In order to evaluate any impairment of usual activities and to thus be able to grade the impairment on the scale provided, it will be important to ask specific questions to learn:

(1) What the patient's home responsibilities, hobbies, and other recreational activities were before becoming aware of his/her shortness of breath,

(2) Whether the shortness of breath has impaired the performance of those activities or whether some other cause or disability is mainly responsible for impairment,

(3) If there has been an impairment, what is the specific type and degree of impairment is, namely:

(a) Are there any activities done more slowly as a result of shortness of breath?

(b) If so, is it most or all usual activities?

(c) Does the patient still do all his/her usual activities, or has (s)he abandoned any completely on account or shortness of breath?

(d) If some activities have been abandoned, is it only a few or is it most, or even all of them that have been given up?

(e) What assistance, if any, does the patient need in performing usual activities, e.g., is (s)he homebound unless helped?

Based on the answers to these questions, it will be possible to decide whether there has been any impairment of home activities, whether the impairment has been due to shortness of breath (or some other cause) and how extensive the impairment has been. With this information, in turn, it will be possible to assign a specific grade for functional impairment at home based on the coding criteria that follow.

V. CRITERIA FOR GRADE ASSESSMENT: Functional Impairment at Home

_____ **Grade 4:** **No Impairment**. The patient is able to carry out usual work activities without shortness of breath; there is no curtailment of the number or type of home activities, and no reduction in pace with which the activities are done.

_____ **Grade 3:** **Slight Impairment**. The patient recognizes that shortness of breath has caused him/her to alter the usual home activities in any of the following way(s):

(a) Although no usual activities have been completely abandoned as a result of shortness of breath, up to several (but not all) activities are done more slowly due to shortness of breath.

(b) Although the patient continues all his/her activities, at least one activity may be done less frequently as a result of shortness of breath.

Example: The devoted baseball fan who, on account of shortness of breath, now goes only to an occasional game rather than his previous pattern of going to every one would be graded as having slight impairment (grade 3) in functional impairment at home.

_____ **Grade 2:** **Moderate Impairment**. Shortness of breath has caused the patient to curtail activities in at least one of the following ways:

(a) Up to several (but not all) of the patient's activities have been completely abandoned because of shortness of breath, and/or

(b) Most or all usual activities are done more slowly because of shortness of breath.

Example: A patient attended the theater regularly before the onset of dyspnea but no longer attends because of his pulmonary disability. Since, however, he stills maintains his woodworking hobby at home (even though he uses the tools more slowly), he should be graded as having moderate impairment.

_____ **Grade 1:** **Severe Impairment**. Shortness of breath has caused the patient to abandon most or all of his/her usual activities.

Examples would include:

(a) The patient who is too breathless to leave the house without assistance.

(b) The patient who, as a result, of shortness of breath, has come to depend on a spouse or assistant to exclusively take over the tasks of shopping, cooking, and cleaning, and who may even need help dressing or washing up because of breathlessness.

_____ **W:** **Amount Uncertain**. Patient's ability to perform tasks is impaired due to shortness of breath, but amount cannot be specified. Details are not sufficient to allow impairment to be categorized.

_____ **X:** **Unknown**. Information unavailable regarding information of magnitude of task.

_____ **Y:** **Impaired for Reasons Other than Shortness of Breath**. Grade Y is assigned if the patient has a limitation in home activities and the main cause of the limitation is a disability other than shortness of breath as, for example, hip disease or some other musculoskeletal impairment, or chest pain. Please describe the nature of this other limiting condition(s):

_____

_____

The Clinical Coordinating Center will be responsible for determining the complete functional grade. For further information refer to your Training Manual.

VI. MAGNITUDE OF TASK: Instructions To The Interviewer

This part of the questionnaire asks you to clarify the threshold at which activity makes the patient short of breath. Specifically, you are asked to find out which of the following types of task is the least strenuous that makes the patient short of breath but which (s)he can nevertheless complete.

In order to assign a grade in this portion of the questionnaire, you will have to identify which of the following types of activities satisfies this criterion.

In order to best ascertain this, we suggest you start your questioning with the least strenuous tasks, e.g., sitting, lying, etc., and, if the patient can complete these without breathlessness, that you then escalate the activity to these corresponding to he next ascending grade.

VII. CRITERIA FOR GRADE ASSIGNMENT: Magnitude of Task

_____ **Grade 4:** **Extraordinary**. Becomes short of breath only with extraordinary activity, such as:

- carrying very heavy loads on the level
- carrying lighter loads upstairs
- running

_____ **Grade 3:** **Major**. Becomes short of breath only with major activities, such as:

- walking up a steep hill
- climbing two flights of stairs or more
- carrying a heavy bad of groceries on the level

_____ **Grade 2:** **Moderate**. Becomes short of breath with moderate or average tasks, such as:

- climbing up stairs to two flights
- walking up a gradual hill
- walking briskly on the level
- carrying a light load on the level

_____ **Grade 1:** **Light**. Becomes short of breath with light activities such as:

- walking on the level with others of the same age
- walking to the bathroom in residence
- washing up
- dressing
- shaving

_____ **No Task**. Becomes short of breath with no activity, as:

- while sitting and/or lying down
- while standing motionless

VIII. MAGNITUDE OF EFFORT: Instructions To The Interviewer

In this portion of the questionnaire, we ask you to find out how limited the patient is in doing the most strenuous task (s)he can initiate and perform for at least five minutes. The patient need not be able to complete this task but only to initiate it on occasion and engage in it for 5 minutes or more at once. To grade the patient accurately, you should have:

(1) Find out what the most strenuous task (s)he initiates and performs for at least five minutes is, and

(2) Find out how much (s)he must exert him/herself to perform task, i.e.,

(a) must (s)he slow down at all in doing this task because of shortness of breath?

(b) must (s)he stop to catch his/her breath?

If the patient is short of breath at rest, enter grade 0. If the impairment is due to some cause other than shortness of breath, enter grade Y and specify the other limiting condition in the space provided.

IX. CRITERIA FOR GRADE ASSIGNMENT: Magnitude of Effort

FOR THE MOST STRENUOUS TASK THE PATIENT CAN PERFORM (FOR AT LEAST FIVE MINUTES):

_____ **Grade 4**: It is done briskly without pausing because of shortness of breath or even slowing down to rest.

_____ **Grade 3**: It is done slowly but without pausing or stopping to catch breath.

_____ **Grade 2**: It is done slowly and still with rare pauses (one or two) to catch breath before completing the task or quitting altogether.

_____ **Grade 1**: It is done slowly and with many stops or pauses before the task is completed or abandoned.

_____ **Grade 0**: The patient is short of breath at rest, or while sitting, or lying down.

_____ **W:** **Amount Uncertain**. Patient's exertional ability is impaired due to shortness of breath, but amount cannot be specified. Details are not sufficient to allow impairment to be categorized.

_____ **X:** **Unknown**. Information unavailable regarding limitation of effort.

_____ **Y:** **Impaired for Reasons Other Than Shortness of Breath**. Grade Y is assigned if the patient is limited in performing his/her most strenuous activity but the main cause of the limitation is a disability other than shortness of breath such as, for example, hip disease, or some other musculoskeletal impairment, or chest pain.

Please describe the nature of this other limiting condition(s):

_____

_____

_____

Note, too, that the condition other than breathlessness that limits the patient's most strenuous condition may not be the same disability that limits the other activities described in this questionnaire. For example, the patient whose angina only occurs with strenuous activity may have little functional limitation at a sedentary job (Grade 4 for "functional impairment at work") but be limited in his/her most strenuous activity by angina (Grade Y on "magnitude of effort": chest pain).

ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
Modified Dyspnea Index Short Form

This form should be completed for each patient visit.

1. Date form completed: complete (fuzzed) ___ ___/ ___ ___/ ___ ___ (month / day / year)

2. Patient Registry ID: Newid (scrambled) ___ ___ ___ ___ ___

3. Patient name code: namecode (censored) ___ ___ ___ ___

4. Clinical Center code number: clinic (censored) ___ ___

5. a. Date of visit: visit (fuzzed) ___ ___/ ___ ___/ ___ ___ (month / day / year)
   visit number vsno

   b. Type of visit: F04Q05B ___(1)Initial ___(2)Follow-Up

6. a. Functional impairment at **WORK** (check only one): F04Q06A

   ___ Grade 4 No impairment
   ___ Grade 3 Slight impairment
   ___ Grade 2 Moderate impairment
   ___ Grade 1 Severe impairment
   ___ W Amount of impairment uncertain
   ___ X Information unavailable
   ___ Y Impaired for reasons other than shortness of breath
   ___ Z Patient did not have a job prior to and after development of shortness of breath, and dyspnea has not affected later plans to start work.

6. b. Functional impairment at **HOME** (check only one): F04Q06B

   ___ Grade 4 No impairment
   ___ Grade 3 Slight impairment
   ___ Grade 2 Moderate impairment
   ___ Grade 1 Severe impairment
   ___ W Amount of impairment uncertain
   ___ X Information unavailable
   ___ Y Impaired for reasons other than shortness of breath

White/Yellow: Clinical Coordinating Center, Pink: Clinical Center

PWO 1868

Patient Registry ID: ___ ___ ___ ___ ___
Date of Visit: ___ ___/ ___ ___/ ___ ___
month day year

7. Magnitude of Task (Check only one category): F04Q07

___ Grade 4 Extraordinary

___ Grade 3 Major

___ Grade 2 Moderate

___ Grade 1 Light

___ Grade 0 No Task

___ W Magnitude of task uncertain

___ X Information unavailable

___ Y Reasons other than shortness of breath

8. Magnitude of Effort (Check only one category): For Most Strenuous Task Patient Can Perform F04Q08

___ Grade 4 Briskly without pause

___ Grade 3 Slowly without pause

___ Grade 2 Slowly with rare pauses (1 or 2)

___ Grade 1 Slowly with many pauses or stops

___ Grade 0 Shortness of breath at rest or while sitting or lying

___ W Magnitude of effort uncertain

___ X Information unavailable

___ Y Reasons other than shortness of breath

MDI 1 } SEE FOLLOWING PAGE FOR EXPLANATION ON THESE VARIABLES.
MDI 3 }

Comments: never entered

Form Completed By (Name): never entered

Physician Signature: never entered

White/Yellow: Clinical Coordinating Center, Pink: Clinical Center

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Notes on Coding:

Additional Calculated Variables included in the Form 4 database:

MDI1 = Composite functional impairment, calculated from F04Q06A and F04Q06B as indicated in the table below.

Format: Character variable, possible values as indicated in the table below

MDI = Total Score - Calculated as the sum of the composite functional grade (MDI1), the magnitude of task (F04Q07), and magnitude of effort (F04Q08), provided all three take on numeric values between 0 and 4.

Format: Numeric, an integer ranging from 0 to 12

Calculation of Composite Functional Grade, MDI1, from the Work and Home Functional Grades

F04Q06A Work Functional Grade	F04Q06B Home Functional Grade	MDI1 Composite Functional Grade
2, 3, or 4	2, 3, or 4	Min(F04Q06A, F04Q06B)
1	2, 3, or 4	1
2, 3, 4	1	1
1	1	0
2, 3, or 4	W, X, or Y	F04Q06A
W, X, Y, or Z	1, 2, 3, or 4	F04Q06B
W, X, Y, or Z	W, X, or Y	Assign two-letter code, in order with work grade first, i.e., if 6a=W, 6b=X, then MDI1=WX

Reference: Stoller et al. *Am Rev Respir Dis* 134: 1129-1134, 1989.