#### FUNCTIONAL LIMITATIONS PROFILE (FLP)

This document describes the Functional Limitations Profile (FLP), a British Version of the Sickness Impact Profile, translated into British English and rescored using British item weights.

This packet contains interview instructions, scoring instructions, and the FLP items. A list of publications concerning the development and use of the FLP is available upon request. The Functional Limitations Profile is a copyrighted instrument in the United Kingdom (Crown Copyright) and in the United States (Johns Hopkins University). Users are requested not to make changes to instructions, items, or scoring without consultation. Reprints of articles published using the FLP are welcome with the cost of the reprint and mailing reimbursed upon request. If you have additional questions, please feel free to contact me by phone, fax, Internet, or mail.

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#### INSTRUCTIONS FOR ADMINISTRATION

The following instructions are for the INTERVIEWER-ADMINISTERED QUESTIONNAIRE (**NOTE**: These differ from the Sickness Impact Profile to permit response to each item rather than responses only to items considered to apply to the respondent and are related to health. This change was made to improve the validity of responses from older adults and persons with disabilities.)

Similar instructions can be used for self administered versions and the form modified for self-administration.

#### SAY TO ALL VERBATIM

I want to talk to you about the things you usually do every day. I am going to read out some statements which describe things people often do when they are not well. Even if you think you are well, some of these statements may stand out, because they describe you and are related to your health. Listen to each statement, think of yourself today and tell me if it describes you or not. For example, I might read the statement, "I am not driving my car." If you agree with this statement, you should tell me (agree/disagree is the best response pattern). I will then ask, "Is this due to your health?" Please answer "yes" or "no." If you have not been driving for some time due to your health and are still not driving today, you should respond "agree." (If respondents have never driven a car but have used public transportation such as a bus or train, substitute "using public transport").

(IF RESPONDENT IS IN HOSPITAL) If you are in hospital today, you are here because of your state of health, and you are not doing a number of the things you usually do. For instance, if driving is usual for you, then you are <u>not</u> driving today because you are in hospital, and you should agree with this statement.

If you never drive or are not driving today because your car is being repaired, you should not respond that the statement is due to your health.

Ask me to repeat a statement or slow down if you do not understand. Remember we are interested in both recent and longstanding changes in your health.

The following instructions are for the SELF-ADMINISTERED QUESTIONNAIRES:

### <u>Introduction to the Respondent</u>

We are interested in the activities that you do in carrying on your life and any changes that describe you today that are related to your health.

This booklet lists statements that describe things people often do when they are not well. Even if you think you are well, some of these statements may stand out, because they describe you and are related to your health. As you read each statement in the questionnaire, think of yourself today. When you read a statement that **describes you and is related to your health**, place a tick on the line to the right of the statement. For example:

I am not driving my car	
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If you have not been driving for some time because of your health and are still not driving today, you should tick this statement. On the other hand, if you never drive or are not driving today because you car is being repaired, you should <u>not</u> tick it. Tick a statement <u>only</u> if you are <u>sure</u> it describes you and is due to health.

NOTE: At the bottom of each page of the self-administered questionnaire, you may wish to ask the respondent to indicate that he or she has read all statements on the page by ticking the following statement:

TICK HERE WHEN YOU HAVE READ [COMPLETED FOR SELF AI	DMINISTRATION]
ALL STATEMENTS ON THIS PAGE	

This helps to ensure that respondents have read all the items on the page and that a page with no ticks does not indicate missing data.

#### OTHER CONSIDERATIONS

The Functional Limitations Profile, based on the same theoretical development but with different psychometric properties from the Sickness Impact Profile, was developed to give a point-in-time estimate of sickness-related dysfunction. The focus on "today" is used to help ensure that all respondents are using the same reference point and recall period. For items that ask for change, i.e., "eating less than usual", the respondent is requested to think of their behavior or health on the day of the enquiry and compare it with what they have done usually prior to the day of enquiry. This prior period may vary for each respondent and contribute to their response concerning "today".

It is extremely important in interviewer-administration of the FLP that interviewers do not break their rhythm in reading items and obtaining responses. It is advisable to establish a pattern of questioning, avoiding eye contact if possible, at this point of the interview.

Many queries may arise when administering the FLP in-person or supervising self-administration of the instrument.

Following are some standardized responses when queries arise.

## ANSWERING QUERIES THAT MAY ARISE

"<u>I've never been able to do that</u>." <u>SAY</u>: Yes, we do want to know about things you have never been able to do.

"I've not been able to do that for some time." SAY: We want to know about all recent or long-standing changes in the things you do.

"Some days I can do that, some days I can't." SAY: Think of yourself today.

"It's due to my age." SAY: Would you say that was due to your health or not?

"None of this applies to me; I'm perfectly health." SAY: A few of the statements may apply to you. It is therefore important that we do check them all, since we are comparing healthy people with less healthy people.

"I retired because of my age, not my health" "I have never been employed for wages." SAY: None of the statements in the work category apply to you. Therefore you do not tick (respond to) any of these items because they do not apply to you.

#### SCORING INSTRUCTIONS

There are twelve category scores, two dimension scores, and an overall FLP score are derived using British weights. These weights are not identical to those used for the Sickness Impact Profile, since they were derived from a British population.

#### CATEGORY SCORES

The percent score is calculated for each category by adding the scale values for each item with which the respondent agrees and considers due to his/her health (or ticked items) and dividing by the maximum possible dysfunction score for the FLP. This figure is then multiplied by 100 to obtain the FLP category score.

#### **DIMENSION SCORES**

Two dimension scores may be calculated. The <a href="physical">physical</a> dimension score is obtained by adding the scale values for each item with which the respondent agrees and considers due to his/her health (or ticked items) with the categories of AMBULATION, BODY CARE AND MOVEMENT, MOBILITY, AND HOUSEHOLD MANAGEMENT, dividing by the maximum possible dysfunction score for these categories (4355), and then multiplying by 100. The <a href="psychosocial">psychosocial</a> dimension score is obtained by adding the scale values for each item ticked within RECREATION AND PASTIME, SOCIAL INTERACTION, EMOTION, ALERTNESS, AND SLEEP AND REST, dividing by the maximum possible dysfunction score for these categories (3667), and then multiplying by 100. The scores for the remaining categories are always calculated individually.

#### OVERALL FLP SCORE

The overall score for the FLP is calculated by adding the scale values for each item with which the respondent agrees and considers due to his/her health (or ticked items) across all 12 categories and dividing by the maximum possible dysfunction score for the FLP (9933). This figure is then multiplied by 100 to obtain the FLP overall score.

Each item within the 12 categories is listed on the following pages along with the scale values coded to one decimal as follows:

- 1. Only items with which the respondent agrees and considers due to his/her health (or ticked items) should be included in the calculations for FLP category, dimension, and overall score.
- 2. Following each item is the scale value or weight for that item e.g., item 1 has a scale value of 5.4.
- 3. The maximum possible scale value is shown following the title of each category e.g., the ambulation category has a maximum possible score of 100.6.

- 4. The maximum possible score for the physical dimension is 444.5 while the maximum possible score for the psychosocial dimension is 366.7.
- 5. The maximum possible score for the FLP is 9933 which is the denominator for calculating the percent score for the entire FLP.
- 6. A special case of category and FLP overall score concerns the work category. Item 128 has a weight of 361 indicating an unusually high scale value. The scale value for this item has been statistically adjusted to take into account the fact that when item 128 is ticked no other item in the work category can been ticked. Please note that the maximum possible score for the work category is not the sum of the individual items, but is instead 70% of the total. This value was determined using the distribution of scores on the work category.

Also, with respect to the work category there are two special considerations in scoring:

1. When a respondent agrees with either,

"If you are retired, was your retirement due to your health? or

"If you are not retired, but are <u>not</u> working, is this due to your health?

he or she is instructed to skip Category W- Work. In scoring the questionnaire for respondents who answer <u>Yes</u> to either of these questions, <u>item 128</u> should be ticked.

# AMBULATION ITEMS (MAXIMUM POSSIBLE SCORE = 1006)

The following statements describe walking and use of stairs. Remember, think of yourself today. If 'AGREE,' PROBE; Is this due to your health?

	IT	EM	WEIG	НТ
1.	I walk shorter distances or often stop for a rest.		-	(054)
2.	I do not walk up or down hills.		-	(064)
3.	I only use stairs with a physical aid; for example, a handrail, stick or crutches.	<b>C</b>	-	(082)
4.	I only go up and down stairs with assistance from someone else.		-	(087)
5.	I get about in a wheelchair.		-	(121)
6.	I do not walk at all.		-	(126)
7.	I walk by myself but with some difficulty; for example, I limp, wobble, stumble or I have a stiff leg.		-	(071)
8.	I only walk with help from someone else.		-	(098)
9.	I go up and down stairs more slowly; for example, one step at a time or I often have to stop.		-	(062)
10.	I do not use stairs at all.		-	(106)
11.	I get about only by using a walking frame, crutches, stick, walls, or hold on to furniture.		-	(096)
12.	I walk more slowly.		-	(039)

# BODY CARE AND MOVEMENT ITEMS (MAXIMUM POSSIBLE SCORE = 1927)

The following statements describe how you move about, bath, go to the toilet, dress yourself today. <u>If 'AGREE', PROBE</u>: Is this due to your health?

13.	I make difficult movements with help; for example getting in or out of the bath or car.	-	(082)
14.	I do not get in and out of bed or chairs without the help of a person or mechanic aid.	-	(100)
15.	I only stand for short periods of time.	-	(067)
16. I	do not keep my balance.	-	(093)
17.	I move my hands or fingers with some difficulty or limitation.	-	(066)
18.	I only stand up with someone's help.	-	(093)
19.	I kneel, stoop or bend down only by holding onto something.	-	(061)
20.	I am in a restricted position all the time.	-	(124)
21.	I am very clumsy.	-	(047)
22.	I get in and out of bed or chairs by grasping something for support or by using a stick or walking frame.	-	(079)
23.	I stay lying down most of the time.	-	(120)
24.	I change position frequently.	-	(05)
25.	I hold onto something to move myself around in bed.	-	(082)
26.	I do not bathe myself completely; for example, I need help with bathing.	-	(085)
27.	I do not bathe myself at all, but am bathed by someone else.	-	(100)
28.	I use a bedpan with help.	-	(107)
29.	I have trouble putting on my shoes, socks, or stockings.	-	(054)
30.	I do not have control of my bladder.	-	(122)
31.	I do not fasten my clothing; for example, I require assistance with buttons, zips or shoelaces.	-	(068)
32.	I spend most of the time partly dressed or in pajamas.	-	(075)
33.	I do not have control of my bowels.	-	(124)
34.	I dress myself, but do so very slowly.	-	(043)

35.	I only get dressed with someone's help.	(082)
TICK	HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PA	.GE

# MOBILITY ITEMS (MAXIMUM POSSIBLE SCORE = 0727)

These next statements describe how you get about the house and outside <u>If 'AGREE' PROBE</u>: Is this due to your health?

36.	I only get about in one building.	-	(076)
37.	I stay in one room.	-	(101)
38.	I stay in bed more.	-	(091)
39.	I stay in bed most of the time.	-	(114)
40.	I do not use public transport now.	-	(052)
41.	I stay at home most of the time.	-	(079)
42.	I only go out if there is a lavatory nearby.	-	(064)
43.	I do not go into town.	-	(047)
44.	I only stay away from home for short periods.	-	(046)
45.	I do not get about in the dark or in places that are not lit unless I have someone to help.	-	(057)

# HOUSEHOLD MANAGEMENT ITEMS (MAXIMUM POSSIBLE SCORE = 0695)

The following statements describe your daily work, around the home. When you answer, think of yourself today. <u>If 'AGREE' PROBE</u>: Is this due to your health?

46.	I only do housework or work around the house for short periods of time or I rest often.	-	(050)
47.	I do less of the daily household chores than I would usually do.	-	(037)
48.	I do not do any of the daily household chores that I would usually do.	-	(090)
49.	I do not do any of the maintenance or repair work that I would usually do in my home or garden.	-	(075)
50.	I do not do any of the shopping that I would usually do.	-	(084)
51.	I do not do any of the cleaning that I would usually do.	-	(078)
52.	I have difficulty using my hands; for example, turning taps, using kitchen gadgets, sewing or doing repairs.	-	(078)
53.	I do not do any of the clothes washing that I would usually do.	-	(075)
54.	I do not do heavy work around the house.	-	(059)
55.	I have given up taking care of personal or household business affairs; for example, paying bills, banking or doing household accounts.	-	(069)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE\_\_\_\_\_

(MAXIMUM POSSIBLE PHYSICAL DIMENSION SCORE = 4355)

# RECREATION AND PASTIME ITEMS (MAXIMUM POSSIBLE SCORE = 0383)

The following statements describe the activities you usually do in your spare time, for relaxation, entertainment or just to pass the time. Again, think of yourself today. <u>If 'AGREE' PROBE</u>: Is this due to your health?

56.	I spend shorter periods of time on my hobbies and recreation.	-	(032)
57.	I go out less often to enjoy myself.	-	(027)
58.	I am cutting down on some of my usual inactive pastimes; for example, I watch TV less, play cards less, or read less.	-	(050)
59.	I am not doing any of my usual inactive pastimes; for example, I do not watch TV, play cards, or read.	-	(091)
60.	I am doing more inactive pastimes instead of my other usual activities.	-	(043)
61.	I take part in fewer community activities.	-	(025)
62.	I am cutting down on some of my usual physical recreation or more active pastimes.	-	(034)
63.	I am not doing any of my usual physical recreation or more active pastimes.	-	(081)

# SOCIAL INTERACTION ITEMS (MAXIMUM POSSIBLE SCORE = 1289)

	statements describe your contact with family and friends today. <u>If 'Ague to your health?</u>	<u> GREE' F</u>	PROBE: Is
64.	I go out less often to visit people.	-	(031)
65.	I do not go out at all to visit people.	-	(091)
66.	I show less interest in other people's problems; for example, I don't listen when they tell me about their problems; I don't offer to help.	-	(050)
67.	I am often irritable with those around me; for example, I snap at people or criticize easily.	-	(064)
68.	I show less affection.	-	(044)
69.	I take part in fewer social activities than I used to; for example, I go to fewer parties or social events.	-	(025)
70.	I am cutting down the length of visits with friends.	-	(031)
71.	I avoid having visitors.	-	(073)
72.	My sexual activity is decreased.	-	(064)
73.	I often express concern over what might be happening to my health.	-	(044)
74.	I talk less with other people.	-	(044)
75.	I make many demands on other people; for example, I insist that they do things for me or tell them how to do things.	-	(076)
76.	I stay alone much of the time.	-	(091)
77.	I am disagreeable with my family; for example, I act spitefully or stubbornly.	-	(086)
78.	I frequently get angry with my family; for example, I hit them, scream or throw things at them.	-	(103)
79.	I isolate myself as much as I can from the rest of my family.	-	(100)
80.	I pay less attention to the children.	-	(059)
81.	I refuse contact with my family; for example, I turn away from them.	-	(109)
82.	I do not look after my children or family as well as I usually do.	-	(066)
83. TICK	I do not joke with members of my family as much as I usually do. HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS	- PAGE_	(038)

# EMOTION ITEMS (MAXIMUM POSSIBLE SCORE = 0693)

The next statements describe your feelings and behavior. Again, think of yourself today. <u>If 'AGREE' PROBE</u>: Is this due to your health?

84.	I say how bad or useless I am; for example, that I am a burden on others.	-	(089)
85.	I laugh or cry suddenly.	-	(058)
86.	I often moan and groan because of pain or discomfort.	-	(067)
87.	I have attempted suicide.	-	(141)
88.	I behave nervously or restlessly.	-	(048)
89.	I keep rubbing or holding areas of my body that hurt or are uncomfortable.	-	(059)
90.	I am irritable and impatient with myself; for example, I run myself down, I swear at myself, I blame myself for things that happen.	-	(079)
91.	I talk hopelessly about the future.	-	(096)
92.	I get sudden frights.	-	(056)

# ALERTNESS ITEMS (MAXIMUM POSSIBLE SCORE = 0711)

93.	I am confused and start to do more than one thing at a time.	-	(074)
94.	I have more minor accidents; for example, I drop things, I trip and fall, or I bump into things.	-	(090)
95.	I react slowly to things that are said or done.	-	(052)
96.	I do not finish things I start.	-	(045)
97.	I have difficulty reasoning and solving problems; for example, making plans, making decisions, or learning new things.	-	(078)
98.	I sometimes get confused; for example, I do not know where I am, who is around, or what day it is.	-	(115)
99.	I forget a lot; for example, things that happened recently, where I put things, or to keep appointments.	-	(085)
100.	I do not keep my attention on any activity for long.	-	(052)
101.	I make more mistakes than usual.	-	(049)
102.	I have difficulty doing things which involve thought and concentration.	-	(071)

# SLEEP AND REST ITEMS (MAXIMUM POSSIBLE SCORE = 0591)

These statements describe your sleep and rest activities today. <u>If 'AGREE' PROBE</u>: Is this due to your health?

	103.	I spend much of the day lying down to rest.	-	(096)
	104.	I sit for much of the day.	-	(062)
	105.	I sleep or doze most of the time, day and night.	-	(111)
	106.	I lie down to rest more often during the day.	-	(072)
	107.	I sit around half asleep.	-	(084)
	108.	I sleep less at night; for example, I wake up easily, I don't fall asleep for a long time, or I keep waking up.	-	(086)
	109.	I sleep or doze more during the day.	-	(080)
r	ГІСК	HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS	PAGE	

(MAXIMUM POSSIBLE PSYCHOSOCIAL DIMENSION SCORE = 3667)

# EATING ITEMS (MAXIMUM POSSIBLE SCORE = 0706)

The following statements describe your eating and drinking habits. <u>If 'AGREE' PROBE</u>: Is this due to your health?

110. I eat much less than usual.	-	(034)
111. I feed myself but only with specially prepared food or special utensils.	-	(076)
112. I eat special or different food; for example, I follow a soft food, bland, low salt, low fat, or low sugar diet.	-	(052)
113. I eat no food at all, but I take liquids.	-	(113)
114. I just pick or nibble at my food.	-	(039)
115. I drink less fluids.	-	(033)
116. I feed myself with help from someone else.	-	(095)
117. I do not feed myself at all but have to be fed.	-	(121)
INTERVIEWER MAY CODE:		
118. I eat no food at all except by tubes or intravenous infusion.	-	(143)

# COMMUNICATION ITEMS (MAXIMUM POSSIBLE SCORE = 0685)

I am going to read out some statements about how much you talk to other people and write. Please think about yourself today. <u>If 'AGREE' PROBE</u>: Is this due to your health?

-	(050)
-	(127)
-	(094)
-	(059)
-	(084)
-	(059)
-	(076)
-	(089)
-	(047)
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## WORK ITEMS (MAXIMUM POSSIBLE SCORE = 0520)

I am going to read out some statements about work. As I read them out think of yourself today. If today is not a working day for you, think about your last working day. <u>If 'AGREE' PROBE</u>: Is this due to your health?

SELF ADMINISTERED: The next group of statements has to do with any work you usually do other than managing your home. By this we mean anything that you regard as work that you do on a regular basis.

Do you usually do work other than managing your home? YES NO

#### IF YES, COMPLETE THE WORK SECTION BELOW STARTING WITH ITEM 129

# IF NO , I USUALLY DO NOT WORK OTHER THAN MANAGING MY HOME PLEASE COMPLETE ITEM 128 :

Are you retired?	YES	NO
If you are retired, was your retirement due to your health?	YES	NO
If you are not retired, but are not working, is this due to your health?	YES	NO
128. I do not work at all (INCLUDES RETIRED BECAUSE OF HEALTH)	F -	(361)
129. I do part of my job at home.	-	(040)
130. I am not getting as much work done as usual.	-	(041)
131. I often get irritable with my workmates; for example, I sna at them or criticize them easily.	p -	(042)
132. I work shorter hours.	-	(052)
133. I only do light work.	-	(056)
134. I only work for short periods of time or often stop to rest.	-	(065)
135. I work at my usual job but with some changes; for example I use different tools or special aids or I swap jobs with someone else.	e, -	(036)
136. I do not do my job as carefully and accurately as usual.	-	(050)

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE\_\_\_\_\_(MAXIMUM POSSIBLE FLP SCORE = 9933)

#### **Publications on the FLP**

- 1. Patrick D. Standardization of comparative health status measures: using scales developed in America in an English speaking country. Pp. 216-220 in Health survey research methods: third biennial conference. Hyattsville, Md.: U.S. Department of Health and Human Services Publication No. (PHS) 81-3269, 1981.
- 2. Patrick, D. (d), The Longitudinal Disability Interview Survey:: Phase I Report. London: Social Medicine and Health Services Research Unit, St. Thomas's Hospital Medical School, 1981.
- 3. Patrick D. (ed) The Longitudinal Disability Interview Survey: Phase II Report London: Social Medicine and Health Services Research Unit, St. Thomas's Hospital Medical School 1982.
- 4. Charlton J., Patrick D., Peach H. Use of mutivariate measures of disability in health surveys. J. Epidemiology and Community Health 37(4): pp. 296-304, 1983.
- 5.. Peach H. The relationship between impairment and disability among disabled persons in the community. Ph.D. Thesis, University of London, 1984.
- 6. Morgan M., Patrick D., and Charlton J. Social networks and psychosocial support among disabled people. Social Science and Medicine, 19:pp. 489-497, 1984.
- 7. Wiggins R.D. A replicated study of the impact of interviewer variability in a community survey of the physically handicapped in an Inner London Borough. Research Working Paper No. 24, London: Polytechnic of Central London, May 1985.
- 8. Patrick D., Sittampalam Y., Somerville S., Carter W., and Bergner M. A cross-cultural comparison of health status values. American Journal of Public Health, 75(12):1402-1407, 1985.
- 9. Patrick D., Morgan M., Charlton J. Psychosocial support and change in the health status of physically disabled people. Social Science and Medicine. 22: 1347-1354, 1986.
- 10. Patrick D., and Peach H. (eds) Disablement in the Community. Oxford: Oxford University Press, 1989.

#### **Known Publications using the Functional Limitations Profile**

- 1. Hutchinson J, Hutchinson M. (1995). The functional limitations profile may be a valid, reliable and sensitive measure of disability in multiple sclerosis. *Journal of Neurology*. 242: 650-657.
- 2. Jones C, Hussey R, Giffiths RD. (1993). A tool to measure the change in health status of selected adult patients before and after intensive care. *Clinical Intensive Care*. 4(4): 160-165.
- 3. Bardsley MJ, Astell S, McCallum A, Home PD. (1993). The performance of three measures of health status in an outpatient diabetes population. *Diabetic Medicine*. 10(7): 619-626.
- 4. Fitzpatrick R, Ziebland S, Jenkinson C, Mowat A. (1992). Importance of sensitivity to change as a criterion for selecting health status measures. *Quality in Health Care*. 1(2): 89-93.
- 5. Williams SJ, Bury MR. (1989). Impairment, disability and handicap in chronic respiratory illness. *Social Science and Medicine*. 29(5): 609-615.
- 6. Fitzpatrick R, Newman S, Lamb R, Shipley M. (1989). A comparison of measures of health status in rheumatoid arthritis. *British Journal of Rheumatology*. 28(3): 201-206.

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