

## SELF-ADMINISTERED QUESTIONNAIRE PROTOCOL

### 1. General

Review all sections of the take-home questionnaire for completeness. Check to see that all questions have been answered that should be answered. Do not probe further on questions that appear to be answered completely unless:

- (1) the question is answered "don't know"
- (2) there is an obvious contradiction between responses to factual questions. Most of the possible conflicts will be outlined below.
- (3) special instructions are given (below).

For "don't know" answers, check to see if the respondent understood the question by reading the question out loud to the participant in interview format. If a question has not been answered that should have been, read the question to the participant. Handle the responses in the same manner as you would any interview question.

For all open ended questions or "other" responses, if the response fits into one of the given categories, code it as such.

As always, our goal is to clarify discrepancies with the participant while he is in clinic. Thus, as outlined below, certain questions should be cross-checked while the participant is in the clinic so any discrepancies can be clarified immediately.

Many of the questions are framed in a certain period of time. Please make sure that the participant understands these time frames.

The participant will complete the self-administered questionnaire in pencil. This pencil will be included in the materials mailed to the participant prior to the visit. The clinic staff will review the questionnaire with the participant when he is in the clinic. At this time, the clinic staff will enter the participant's responses in pen.

### 2. Missing data

Leave boxes and circles blank that are NOT APPLICABLE (for example, questions that should be skipped because of the response to a stem question).

For boxes, if a participant REFUSES or DOESN'T KNOW the answer to a question LEAVE IT BLANK. Do not fill in any codes for any forms.

### **Specific Questions for Baseline Self-Administered Questionnaire**

#### **3.01 General Information**

##### **Q1. Name, Address, Phone Number, Fax Number and E-mail address**

The participant's name, address, and phone number should be legible. Review the address for accuracy and legibility. This address should be where the respondent can be located and mailed study materials for most of the year. **Be sure zip code is included.** For participants who do not have telephones, it is acceptable if they give us the number of someone who can get a message to him.

##### **Q2. "Next of kin": Name, address, and telephone number**

Next of kin should be the relative with whom the participant has the most frequent contact, who would know his health and vital status and who would know the respondents new address if he moved. It will help to know the exact relationship of the next of kin to the participant.

##### **Q3. Name, address, and telephone number of two close friends or relatives who do not live with respondent**

A contact is someone who would know the participant's new address if he moved; it does not have to be a person who always knows his whereabouts. If a contact person has to be called to track a participant, it will help to know the contact's relationship to the participant. We will collect information on two contacts.

##### **Q4. Doctor/Health Care**

Make sure a name, address, and phone number are recorded, if the participant has a doctor or place that they generally go to for health care.

**Q5. Age and Date of Birth**

Make sure that the age is listed with a four-digit year. Sort out any discrepancy between date of birth and age, and make any changes if necessary. A very few respondents may be reluctant to give their exact birth date or age. In this case, tell the participant that it is essential that you know for certain that he is 65 or older.

**Q6. Social Security and Medicare Numbers**

This information is crucial for tracking the respondents through Social Security and vital statistics data bases. Attempt to verify the accuracy of the social security number by asking to see the social security card.

Most men over age 65 should have a Medicare number, but some may not. This information is also crucial for tracking the respondents through vital statistics data bases. Ask to see the participant's Medicare card, and confirm that the number recorded is accurate.

The purpose of recording the participant's Social Security and Medicare numbers is to provide the study with information about their health and vital status that we might otherwise miss. Reassure reluctant respondents that information obtained as part of this study is strictly confidential and will be used only for research purposes; we will not be sharing any data about them with Medicare or Social Security, nor will it be used to bill for services (participation in the study is free). A small percentage of respondents may have a "non standard" Medicare number that has fewer than 11 characters and does not have the familiar Medicare number format with 1 or 2 additional characters at the end. Record this non-standard Medicare number on the lines provided.

**Q8-9. Marital Status, Living Arrangements**

Only one answer for each question should be marked.

**Q10. Education level**

Include all regular schooling in graded public, private and parochial schools or in colleges, universities or professional schools, whether day or night school. Regular schooling is that which advances a person toward a diploma or degree or the credits obtained are acceptable in the regular school system. Passing a high school equivalency test or completing high

school in the military counts as finishing high school. The equivalent grade in the regular school system should be selected for respondents who obtained a formal education through foreign schools, ungraded schools, private instruction if counted toward promotion in the regular school system, technical high schools offering a regular high school diploma, or "normal" schools. College course work not taken for credit should not be counted. College should be considered a 4-year bachelor's program. Completion of an AA degree, technical certificate after high school, or other training or apprenticeship program should be considered 'Some college.'

### **Q11. Occupation**

The 1998 Standard Occupational Classification (SOC) System was developed in response to a growing need for a universal occupational classification system. Such a classification system would allow government agencies and private industry to produce comparable data. It is designed to cover all occupations in which work is performed for pay or profit, reflecting the current occupational structure in the United States. We will be using the two digit code for the major occupation group for this study.

In order to ensure that all users of occupational data classify workers the same way, the following classification principles should be followed.

1. The Classification covers all occupations, in which work is performed for pay or profit, including work performed in family-operated enterprises by family members who are not directly compensated. It excludes occupations unique to volunteers. Each occupation is assigned to only one occupation at the lowest level of the classification.
2. Occupations are classified based upon work performed, skills, education, training, and credentials.
3. Supervisors of professional and technical workers usually have a background similar to the workers they supervise, and are therefore classified with the workers they supervise. Likewise, team leaders, lead workers and supervisors of production, sales, and service workers who spend at least 20 percent of their time performing work similar to the workers they supervise are classified with the workers they supervise.

4. First-line managers and supervisors of production, service, and sales workers who spend more than 80 percent of their time performing supervisory activities are classified separately in the appropriate supervisor category, since their work activities are distinct from those of the workers they supervise. First-line managers are generally found in smaller establishments where they perform both supervisory and management functions, such as accounting, marketing, and personnel work.
5. Apprentices and trainees should be classified with the occupations for which they are being trained, while helpers and aides should be classified separately.
6. If an occupation is not included as a distinct detailed occupation in the structure, it is classified in the appropriate residual occupation. Residual occupations contain all occupations within a major, minor or broad group that are not classified separately.
7. When workers may be classified in more than one occupation, they should be classified in the occupation that requires the highest level of skill. If there is no measurable difference in skill requirements, workers are included in the occupation they spend the most time.
8. Data collection and reporting agencies should classify workers at the most detailed level possible. Different agencies may use different levels of aggregation, depending on their ability to collect data, and the requirements of users.

Here is a list of occupation codes:

<u>Code</u>	<u>Occupation</u>
11	<b>Management Occupations:</b> Legislators, operations managers, public relations, advertising managers, human resources managers, information systems managers, education administrators, farmers, funeral directors.
13	<b>Business and Financial Occupations:</b> Purchasing agents, claims adjusters, HR specialists, convention planners, accountants, appraisers, financial analysts, tax preparers.
15	<b>Computer and Mathematical Occupations:</b> Computer specialists and programmers, software engineers, systems analysts, statisticians, actuaries, research analysts, mathematical technicians.

- 17 **Architecture and Engineering Occupations:** Architects, surveyors, drafters, engineers, mapping technicians.
- 19 **Life, Physical, and Social Science Occupations:** Biologists, astronomers, physicists, chemists, economists, market and research analysts, psychologists.
- 21 **Community and Social Service Occupations:** Counselors, social workers, clergy, religious.
- 23 **Legal Occupations:** Lawyers, judges, paralegals, legal assistants and support.
- 25 **Education, Training and Library Occupations:** Postsecondary teachers, school teachers, librarians, curators, archivists, instructional coordinators
- 27 **Arts, Design, Entertainment, Sports and Media Occupations:** Artists, designers, actors, producers, directors, coaches, umpires, dancers, athletes, musicians, singers, PR specialists, announcers, writers, editors, interpreters, photographers.
- 29 **Healthcare Practitioners and Technical Occupations:** Chiropractors, dentists, orthodontists, dietitians, optometrists, pharmacists, physicians, surgeons, nurses, podiatrists, therapists, veterinarians, health technicians, paramedics, psychiatrists
- 31 **Healthcare Support Occupations:** Health aides and assistants, massage therapists.
- 33 **Protective Service Occupations:** Law enforcement workers, police, firemen, security guards, crossing guards, animal control workers, life guards.
- 35 **Food Preparation and Serving Related Occupations:** Chefs, bartenders, cooks, waiters, dishwashers, hosts.
- 37 **Building and Grounds Cleaning and Maintenance Occupations:** Janitors, cleaners, maids, housekeepers, pest control, tree trimmers, landscapers.
- 39 **Personal Care and Service Occupations:** Animal trainers, non-farm animal caretakers, gaming services workers, motion picture projectionists, ushers, ticket takers, embalmers, barbers, cosmetologists, bellhops, concierge, child care workers, fitness trainers

- 41           **Sales and Related Occupations:** Cashiers, rental clerks, sales agents, travel agents, sales representatives, models, real estate brokers and agents
- 43           **Office and Administrative Support Occupations:** Switchboard operators, answering service workers, bookkeepers, accounting clerks, tellers, payroll clerks, customer service, file clerks, desk clerks, receptionists, secretaries, data entry clerks, desktop publishers.
- 45           **Farming, Fishing and Forestry Occupations:** Agricultural inspectors, animal breeders, farm contractors, fishers, hunters, trappers, forest conservationists, loggers, fallers.
- 47           **Construction and Extraction Occupations:** Boilermakers, brickmakers, masons, carpenters, electricians, glaziers, painters, plumbers, roofers, miners
- 49           **Installation, Maintenance and Repair Occupations:** Computer repairers, automotive technicians.
- 51           **Production Occupations:** Assembly line workers, bakers, butchers, meat packers, machinists, welders, bookbinders, tailors, woodworkers.
- 53           **Transportation and Material Moving Occupations:** Aircraft pilots and flight engineers, air traffic controllers, bus drivers, ambulance drivers, locomotive engineers, sailors.
- 55           **Military Specific Occupations:** Military officers.

If you are NOT sure how to classify a participant's occupation, refer to the web site <http://www.bls.gov/soc/socguide.htm> or see list at the end of this chapter for more information. Every occupation should fit into one of the above categories.

## Q12. Racial/Ethnic Background

More than one choice may be selected for this question. If the participant has difficulty selecting, indicate that we are interested in whom "most of your ancestors were."

## 3.02 Medical History

### Q1. Various Medical Conditions

Ensure that the Yes/No question is answered for each disease or condition. If the answer is yes, the participant should have indicated if a doctor is currently treating them for this condition.

Below is a description for each condition:

**Diabetes**

Any confirmed diagnosis of diabetes mellitus should be recorded. Do not include "borderline diabetes" unless the participant received a medical treatment (insulin or an oral medication) for this condition.

**High Thyroid, Grave's disease, or overactive thyroid gland**

Hyperthyroidism will almost always have been treated (by surgery, medication, or radiation treatments) if it was diagnosed. Many men who initially suffered from an overactive thyroid will develop an under active thyroid because of the treatment given. Do not include thyroid conditions which are not specifically associated with hyperthyroidism (such as goiter, thyroid nodule or tumor, or problems with metabolism) unless participant was told it was accompanied by an overactive thyroid.

**Low thyroid or under active thyroid gland**

This condition is also known as hypothyroidism. This condition may be the result of hyperthyroidism treatment. Symptoms include weakness and fatigue. Many men with low thyroid will be on medication.

**Osteoporosis, thin or brittle bones**

Osteoporosis is a condition that is characterized by low bone mineral density, the progressive loss of bone density, thinning of bone tissue and increased susceptibility to fracture.

**Stroke, blood clot in the brain or bleeding in the brain**

Stroke refers to neurological abnormality, including weakness, numbness, slurred speech, or partial loss of vision, which lasted as least 24 hours and was diagnosed by a physician at the time it occurred or within a few weeks. Do not include episodes of a "transient ischemic attack" or TIA, which are similar to strokes but are limited to 24 hours or less of symptoms. If the respondent says the doctor told him he had a "mini-stroke", record "NO."

**Parkinson's disease**



Parkinson's disease is a progressive degenerative neurological process, which results in characteristic tremor and gait disturbances. Most, not all, will receive medication for this disorder.

**Hypertension or high blood pressure**

Most men will be aware of a diagnosis of hypertension if it is present. Include treated or untreated hypertension, but do not include men who were told on one or two occasions that they had an elevated blood pressure which later returned to normal and did not require specific treatment. Include men who say they have high systolic (the upper number) blood pressure. The vast majority of men with a diagnosis of hypertension will have been treated with medications, although some will have only received only dietary treatment.

**Heart attack, coronary or myocardial infarction**

Most men will know if they've had an MI. If you are not sure, ask if they spent several days in the hospital; most people with MIs are hospitalized for at least several days.

**Angina (chest pain)**

Characterized by chest pain, often accompanies physical activity or stress. Almost always treated with medication.

**Congestive heart failure or enlarged heart**

Congestive heart failure (CHF) is the inability of the heart to maintain circulation sufficient to meet the body's needs. Marked by breathlessness and abnormal retention of sodium and water, resulting in edema, with congestion in the lungs. Enlarged heart will usually be diagnosed by x-ray. Usually treated with low salt diet, diuretics, and other medications.

**Chronic obstructive lung disease, chronic bronchitis, asthma, emphysema, COPD**

Any diagnosed chronic lung disease: bronchitis-inflammation of the airway passages to and within the lungs; asthma: recurrent attacks of labored or difficult breathing; emphysema-pathologic accumulation of air in tissues or organs. Do not include ACUTE attacks of bronchitis or upper respiratory infection.

**Enlarged prostate**

This condition, also known as benign prostatic hyperplasia (or hypertrophy) is characterized by a benign (not cancerous) growth in the prostate gland. This tumor, although not cancerous, may cause obstruction of the urethra and interfere with the normal flow of urine.

### **Prostatitis**

Acute and chronic prostatitis are generally caused by bacterial infection. Causes of acute prostatitis include sexually transmitted diseases; bacteria that cause urinary tract infections; or as a result of medical instruments (such as a catheter.) Chronic prostatitis is usually caused by bacteria that cause urinary tract infections. A person may have no symptoms of prostatitis.

### **Glaucoma**

Glaucoma is a condition of increased fluid pressure inside the eye, also known as intraocular pressure. This damages the optic nerve causing partial vision loss and eventually blindness. This is the leading cause of blindness in the United States. Most people with glaucoma will be receiving treatment for this condition.

### **Cataracts**

This condition is also known as lens opacity. It is defined by a cloudy area in the lens of the eye. Three classifications for cataracts exist: immature, mature or hypermature. About 50 percent of Americans ages 65 to 74 have cataracts, and about 70 percent of those over age 75 have it. Include if participant has cataracts diagnosed in one or both eyes.

### **Q2. Stomach/Intestines**

Indicate age when stomach/intestines were removed, when appropriate.

### **Q3. Arthritis**

Many men will report some form of joint pain or rheumatism, but only those conditions specifically diagnosed by a physician should be recorded.

For the answer labeled 'Some other type of arthritis' make sure that this 'other' type is not already listed as one of the choices.

### **Q4. Kidney Stones**

Note the five year time period for kidney stones.

### **Q5. Cancer**

Make sure an age at diagnosis is listed if cancer has been diagnosed. For the prostate cancer option, ensure that the participant has noted if he has received treatment for his condition. 'Watchful waiting' (regular check-ups but no medication or treatment) does NOT count as treatment.

#### **Q6. Dizziness**

Note that more than one type of dizziness can be selected.

#### **Q7. Falls**

Note the 12 month time period for the question. More than one type of injury from a fall can be listed. Participants cannot select both and injury and 'I did not have any injuries from a fall in the past 12 months.'

#### **Q8-11 Weight and Height Questions**

Encourage the participant to complete any of these questions that they have left blank. Repeat the instruction to give the best estimate of height, weight, etc.

### **3.03 Prostate Health**

#### **Q1-7. Prostate Symptoms**

Note the 'over the past month' time period for these questions. Make sure that the participant answers all of these questions, even if he does not have any prostate problems or symptoms.

#### **Q8. Prostate Quality of Life**

Again, encourage the participant to answer this question even if he does not mention any prostate symptoms in the previous questions.

#### **Q9-12. Prostate Symptoms**

Note the 'over the past one month' time period for these questions.

### Q13. Prostate Cancer

Make sure that the participant has indicated all relatives that have had prostate cancer; more than one relative can be selected.

### 3.04 Diet History

#### Q1. Special Diet

If the participant is on one or more special diets, please make sure that they have selected all of the special diets that apply. If the participant selects 'Other diet,' make sure that the diet listed is not included as one of the options. If necessary, ask the participant to describe the diet specified under 'other' to ensure that it is not the same as another on the list.

### 3.05 Tobacco & Alcohol Use

#### Q1. Cigarette Smoking

Most people answer this question easily, but some who smoke only on special occasions and/or infrequent occasions may find it difficult to answer. Note that the questions should be answered in terms of cigarettes per day. Answer only in whole numbers, DO NOT use fractions or decimals. You may have to help the participant answer some of these questions, consult the table below.

#### Smoking Habit Conversion

Use per week	Cigarette use per day
Less than ½ pack	1
½ pack	1
1 pack	2
1 ½ packs	4
2 packs	5
2 ½ packs	7
3 packs	8
3 ½ packs	10
4 packs	11

4 ½ packs	12
5 packs	14
1 carton	28
1 ½ cartons	42
2 cartons	56

If answered in terms of a month, divide by 4 to convert to number per day.

**Q2-3. Chewing tobacco, snuff, pipe and cigar use.**

Note that the time period for use for these questions is per week.

**Q4. CAGE alcohol questions.**

The purpose of this set of questions is to determine those participants who may have had alcohol problems. These questions are particularly popular with primary care givers, but are also used in research studies. Keep this section of the questionnaire separate from the alcohol use questions in the clinic interview. If a participant refused to answer these questions, leave them blank.

**3.06 Physical Activity Questionnaire (PASE)**

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**Introduction**

The Physical Activity Scale for the Elderly (PASE) is an easily administered and scored instrument that measures the level of physical activity in individuals aged 65 years and older. The development of this instrument was supported by a Small Business Innovation Research grant from the National Institute on Aging. The instrument is comprised of self-reported occupational, household and leisure activities items over a one-week period and may be administered by telephone, mail, or in person. The PASE can be used to measure physical activity levels in epidemiologic surveys of older people as well as to assess the effectiveness of exercise interventions.

**Administration Instructions**

The PASE instrument may be administered by interview or completed by elderly respondents. Self-administered or interview-administered versions of the instrument can be completed in 5 to 15 minutes.

The leisure activity items require respondents to first report the number of days per week the activity was performed and then the number of hours per day. Space is also provided for respondents to record the types of activities in which they engaged. These reports should be reviewed with the participant before faxing the forms to the Coordinating Center, to ensure that specific sports and recreational activities have been recorded in the appropriate categories.

### Scoring information

#### Q3. Light Sport and Recreation

archery  
badminton  
billiards  
boating (canoeing, rowing, sailing)  
bocci  
bowling  
catch  
croquet  
darts  
fishing  
frisbee  
golf with a power cart  
horseshoes  
musical program  
riflery  
shuffleboard  
swimming; no laps  
table tennis

#### Q5. Strenuous Sport and Recreation

aerobic dance or water aerobics  
backpacking  
basketball  
bicycling/exercise bike  
board sailing  
handball/paddle ball  
racquetball  
hiking  
hockey (field or ice)  
jogging  
lacrosse  
mountain climbing, running  
rope skipping  
rowing machine  
rowing/canoeing for competition  
skiing(cross country, downhill, water)  
snow shoeing  
soccer  
stair climbing  
squash  
swimming laps

#### Q4. Moderate Sport and Recreation

barn chores  
dancing ( ball room, ballet, disco)  
fencing  
football  
golf without a cart  
horseback riding  
hunting  
scuba diving  
skating (ice, roller)  
sledding  
snorkeling  
softball/baseball/cricket  
surfing  
tennis (doubles)  
trampoline  
volleyball

#### Q7. Light Housework

drying dishes  
dusting  
hanging up laundry  
ironing  
laundry  
meal preparation  
washing dishes

#### Q6. Muscle Strength and Endurance

calisthenics  
hand weights  
physical therapy with weights  
push-ups  
sit-ups  
weight-lifting

#### Q8.Heavy Housework

carrying wood  
mopping floors  
moving furniture  
scrubbing floors  
sweeping  
vacuuming

tennis (singles)

washing walls  
washing windows  
washing cars

### PASE coding examples

The following examples are provided as guidelines regarding the administration and coding of the PASE.

**Q1.** Example: Respondent watches the news every day for one hour.

On Tuesday, the respondent plays bingo for three hours.

Also, the respondent attends meetings twice a week. One meeting lasts one hour, and the other meeting lasts two hours.

Since the respondent watches TV every day, the interviewer would code sitting activities as often (5-7 days). During the week, the respondent reported 13 hours of sitting (7 hours of TV watching, 3 hours of bingo, and 3 hours of meetings.) Dividing the total hours/week (13) by the days engaged in sitting activities per week (7) results in hours per day engaged in sitting activities (1.9 hours; between 1 and 2 hours.)

Visiting with others, sewing, paperwork, playing musical instruments, playing cards, and/or bingo are considered sitting activities.

**Q2.** Example: The respondent walks 30 minutes to 1.5 hours per day.

The average time spent walking was 1 hour. Between 1 and 2 hours per day is coded for walking.

Example: Three times a week, the respondent walks 3-4 times a day for 15 minutes.

Throughout PASE, the number of days rather than the number of occasions is coded. Therefore, the respondent walked sometimes (3-4 days). The respondent averaged 52.5 minutes of walking (3.5 times x 15 minutes) on those days, which is coded as less than one hour of walking outside the home or yard.

Any leisure time, household or work related activity that involves waking is coded entirely under the appropriate activity category (light, moderate or strenuous sport or recreation, muscle strength and endurance, or work-related.) Hence, walking as part of golf would be coded only as moderate sport and recreation (Question 4) and not as walking (Question 2.)



**Q3.** Example: The respondent plays golf 4 days per week for 4 hours per day. Three days a week, the golfer uses a power cart. One day a week, the golfer walks the course either pulling a cart, carrying the clubs, or the caddy carries the clubs.

Only golf with the power cart would be coded under light sport and recreation. Specifically, the respondent golfed with a cart sometimes (3-4 days/week) for 2-4 hours/day. Golfing without a cart would be marked under moderate sport and recreation as seldom (1-2 days) for 2-4 hours per day. Putting or hitting golf balls at a driving range are coded for light sport and recreation.

Stretching is not coded under any activity in the PASE.

**Q4.** Gardening and lawn work are not coded under leisure time activities. Gardening and lawn work are considered household activities. Question 9 addresses lawn work and gardening.

**Q5.** Example: The respondent swims laps but considers the activity light rather than strenuous sport and recreation.

Swimming laps is coded a strenuous sport and recreational activity, regardless of the respondent's assessment of the activity's intensity. Leisure time activities and listed in this section.

Example: The respondent participates in a one hour aerobic class, 3 days per week. The class consists of 20 minutes of stretching, 20 minutes of hand weights or calisthenics, and 20 minutes of aerobic dance (exercise).

The aerobic class would be coded under two categories. The 20 minutes of aerobic dance (exercise) would be coded under strenuous activities, and the 20 minutes of calisthenics would be coded under muscle strength and endurance. The 20 minutes of stretching would not be coded under any activity category. Under strenuous activities, the interviewer would list aerobics and mark less than 1 hour per day for 3-4 days per week. Likewise, calisthenics would be listed under muscle strength and endurance for less than 1 hour/day for 3-4 days/week.

Climbing stairs as part of an exercise regimen is coded under strenuous sport and recreation. However, stair climbing as part of daily activities is not coded in the PASE.

**Q6.** Strenuous work activity, such as moving furniture, is not included In this question. Only activities that are done specifically to increase muscular strength and endurance are used in Question 6.

**Q7.** Drying dishes, clothes washing, ironing, hanging up laundry, taking out the garbage, and preparing meals are considered light housework.

**Q8.** See above for applicable activities.

**Q9.** Home repair includes home improvement and maintenance projects such as painting, plumbing and carpentry.

Snow removal (sweeping snow, shoveling snow or using a snow blower) is considered to be lawn work or yard care. Lawn moving is counted as lawn work regardless of the type of mower (riding, power, or push) used.

Stacking wood as a household chore is considered to be heavy housework (Question 8); chopping wood outdoors should be coded under this question.

Example: Respondent does outdoor gardening in season. In February, the respondent has not started the garden yet.

Outdoor gardening is not checked. Only activities performed during the past seven days are coded.

Dependency is defined as a person requiring assistance with activities of daily living (food preparation, personal hygiene, household cleaning.) Division of labor within a household (i.e. meal preparation, laundry, yard work) is not considered dependency.

Babysitting is included in this question. Baby sitting is not included in Question 10 as a work-related activity.

Pet care is not considered part of Question 9.

**Q10.** Only work performed during the past 7 days is coded.

Example: The respondent works half the time sitting or standing with some walking, and the other half of the time walking, with some handling of materials.

Higher rather than lower activity levels are coded if the respondent indicates two categories of physical activity are required on the job or volunteer work.

Respondents should be encouraged to give their best estimate of the number of hours they worked during the previous seven days. However, if a range of hours is reported (e.g. 15-20 hours), use the midpoint of the range as an estimate.

Further information about the PASE instruments can be obtained from:

Washburn RA, Smith KW, Jette AM, Janney CA. The Physical Activity Scale for the Elderly (PASE): Development and Evaluation. *Journal of Clinical Epidemiology*. 46 (2) 153-162. 1993.

### **3.07 Lifestyle**

#### **Q1-12. SF-12**

These questions are designed to assess multiple health concepts and a range of health states pertaining to general functioning and well-being. These questions are the Medical Outcomes Study, Short Form (SF-12), and include six health related concepts: physical functioning, role functioning, social functioning, mental health, health perceptions and pain. Physical functioning is assessed by limitations due to health in a variety of physical activities, ranging from basic to strenuous activities. Role and social functioning are defined by limitations in major role or social activities due to health problems. Mental health is assessed in terms of psychological distress and well being. The measure of health perceptions taps the participant's own ratings of his current health in general. The definitions of physical functioning, mental health and health perceptions tap positive as well as negative states of health.

Definitions: The definitions of these health concepts and the corresponding questions are summarized below,

#### **Physical functioning (Q2-3)**

Extent to which health interferes with a variety of physical activities (such as sports, carrying groceries, climbing stairs, and walking)

#### **Role functioning (Q4-5)**

Extent to which health interferes with major roles and regular daily activity such as work, housework, taking care of family members, volunteer work and taking part in community activities.

#### **Social functioning (Q12)**

Extent to which health interferes with normal social activities such as visiting with friends during the past month.

#### **Mental Health (Q6-7 & 9-11)**

General mood or affect, including anxiety, depression and physiological well-being during the past month.

#### **Health perceptions (Q1)**

Overall ratings of current health in general.

**Pain (Q8)**

Extent of bodily pain in the past four weeks.

**Issues:** Some participants will not be able to describe limitations in their physical functioning due to health reasons because they simply don't do the activity. In general, this will only apply to questions 2, 3 and 8. In this case, the interviewer needs to determine if the subject does not do the activity due to a health or physical problem, or if he does not do the activity for some other reason (such as living in a place where there are no stairs). If the activity is not done for reasons that are not related to health, then ask the subject to project or estimate whether his health would limit him from doing these activities if the opportunity were to arise.

**Q13-17. Functional Status questions**

These questions ask about difficulty in accomplishing selected activities. One frequent area of confusion regarding functional status measures is determining the degree of difficulty for activities that the subject accomplished with help or with special aids. Therefore, we ask about difficulty when the respondent performs the activity **by himself and without using any special aids.**

It is important that the participant answers the questions about the degree of difficulty for the 5 specific activities when he does **NOT** use any aids or receive help.

Be sure the participant understands that the questions are about difficulty he has by himself and without the use of special aids. Aids include a cane, walker, artificial limb, special eating appliances, special reaching appliances, grab bars, automatic lifts, etc.

If a participant says that he can do an activity but only very slowly, ask if he has difficulty doing the activity at a speed that he would consider normal for his age. If he does have difficulty at a normal speed, then mark 'yes.'

**Pain vs. difficulty:** If a participant says he has pain but not difficulty, ask if pain makes the task more difficult or impossible to do. If so, then this is 'difficulty.' If he doesn't do something because of pain, then this should be interpreted as a form of difficulty.

For each question, the participant should determine if he has difficulty doing the activity listed. If he answers YES, he will need to indicate the level of difficulty and then indicate if the difficulty is due to a health or physical problem. If he answers NO, then he should skip to the next question. If the answers I DON'T DO IT, he should indicate if this is because of a health or physical problem.

### **3.08 Fracture History**

#### **Q1. Fractures**

In this section, we ask about bone or bones that participants may have broken. This does not include damage to ligaments or joints that did not involve a fracture or broken bone.

If a participant broke a particular bone in two or more places due to the same trauma, count this as a single fracture incident, only record once.

If the participant broke or fractured a particular bone more than three separate times, list the three most recent fractures.

A brief description of each fracture type follows:

**A. Hip:** Includes trochanteric or femoral neck regions.

**B. Wrist or forearm:** Includes distal radius, and ulna. Does not include the elbow, proximal ulna or radius, or bones of the hand or fingers (metacarpals.)

**C. Spine:** Includes vertebral fractures, thoracic and lumber spine fractures. Does not include tailbone, sacrum or coccyx.

**D. Shoulder or collar bone:** Includes clavicle and scapula. Does not include ribs.

**E. Upper Arm:** Includes proximal and mid and distal humerus, and elbow.

**F. Ribs, Chest or Sternum:** Includes chest plate.

**G. Upper Leg:** Includes femur, including subtrochanteric; does not include hip fractures.

**H. Knee or Knee Cap.** Includes patella and tibial plateau.

**I. Lower Leg.** Includes tibia and/or fibula. Does not include knee or ankle.

**J. Ankle, foot or toes.** Includes very distal tibia and/or fibula, one or more tarsal or metatarsal bones, heel and/or calcaneus, and toes.

**K. Hand or fingers.** Includes one or more of the metacarpal bones.

**L Other bones.** Make sure that the bone(s) the participant broke is not included in any of the other options. Other bones include the bones of the face, skull, sacrum, coccyx and tailbone.

**Trauma Codes:** From the description of how the fracture occurred, assign one of the following trauma codes:

<u>Abbreviation</u>	<u>Trauma</u>
SI	Sports Injury
MVA	Motor Vehicle Accident
SH	Fall from Standing Height
BSH	Fall from Below Standing Height
ASH	Fall from Above Standing Height
OTH	Other trauma

**Examples:**

Response	Coding
Broke wrist playing baseball at age 16	Age is 16; trauma code is SI
Broke both heels in car accident at age 68	List twice, age both incidents is 68, trauma code is MVA
Broke arm four times, at age 12, broke left arm skateboarding; at age 16 broke right arm from football; at age 25 broke left arm from a car accident; at age 31 broke right arm from a car accident.	List three most recent fractures— Age is 16, code is SI; Age 25, code MVA; Age 31, code MVA. Note that we do not ask which side was broken.
Broke upper leg falling down stairs at age 43	Age is 43, trauma code is ASH

Broke knee cap at after tripping on carpet at age 50	Age is 50, trauma code is SH
Broke upper arm falling off toilet at age 73	Age is 73; trauma code is BSH
Broke hand when slammed in car door at age 89	Age is 89; trauma code is OTH

**Q2-9. Family History**

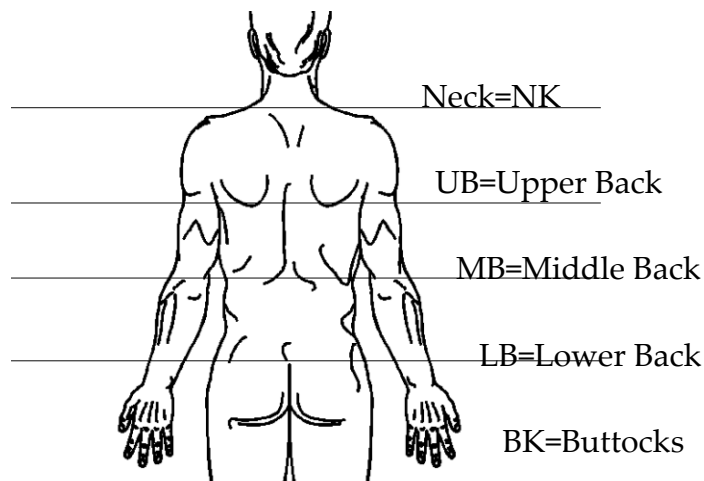
These questions attempt to ascertain family history of osteoporosis. Make sure that the participant answers for his natural or biological parents, not step-parents or adoptive parents.

**Q4 & 7.** If the participant does not know how old his natural mother or father was when he or she died, or how old he or she is now, enter the proper code.

**Q8 & 9.** If the participant does not have any siblings or children, enter '0' for that field. Make sure that the participant has listed only LIVING full brothers and sisters, those that have the same natural parents as the subject. Do not include half-siblings, step siblings, or other siblings who are not blood relatives. For children, do not include step-children or adopted children.

**3.09 Back and Hip Health**

**Q1.** Note the 'past 12 months' time period for this question. The participant will mark the painful area on their back with an 'X'. The mark will then be coded as follows:





If a participant places an 'X' directly over a line, code both areas the 'X' touches.

Ensure that the participant has answered the questions regarding symptoms. If the participant's symptoms are worse for one condition, but the same for another, then code as worse. (For example, the patient has both neck and lower back pain. The neck pain is not affected by leaning forward, but the lower back pain is. Code as 'worse.')

**Q2-10.** These next set of questions aim to ascertain the prevalence of stenosis in the MrOS study. Note the restricted time period (the past 12 months.) Make sure that the participant has answered all of the questions, even if he does not have any of the symptoms listed. If a participant has experienced only numbness or tingling in the arm or hand, without back pain, this should be coded as 'yes' to Question 7 and 'no' to Question 3. If the participant only experiences numbness in the arm or hand with back pain, then this should be coded as 'yes' to Question 3 and 'no' to Question 7. If the participant experiences numbness or tingling in the arm or hand with and without back pain, then both Question 3 and Question 7 should be answered 'yes.' Numbness and tingling are also known as a limb or extremity "falling asleep."

### **Q11. Limited activities due to back problems**

If a participant limited his activities due to back pain, we are interested in the degree of this limitation. The first question asks about the number of days that the participant stayed in bed, for at least half a day, because of back problems. (This also includes time lying down, for example on a couch.) If the participant did not stay in bed for at least half the day on any day in the past 12 months, then enter 0.

The second questions ask on how many days did the participant limit activities because of back pain. This should not include the number of days in bed. Note that the total number of days for these two answers should be less than 365 days. (This maximum will only be obtained by those participants who are affected by back pain on every day in the past 12 months.)

### **Q12. Back health**

This set of questions is designed to ascertain the level of impairment caused by back pain. If a participant does not do an activity for reasons other than health (for example, he never gets in the front seat of a car), ask the participant to imagine his level of difficulty if he had an opportunity to perform the task.

### **Q13. Hip pain**

This question is used to determine the amount of hip pain a participant is experiencing. The hip area is described as the hip joint, including the buttock, groin, or either side of the upper thigh. This area does not include the lower back. The time period is on most days, for at least one month, within the past 12 months. Another way to phrase the time period follows: nearly every day for a month, within the past year. Make sure that the participant understands the time period.

### **Q14. Knee Pain**

The topic of this question is Knee Pain. This includes pain, aching and stiffness in the front, back and side of knee. The time period is the same as the previous question. Make sure the participant understands the time period.

## **4.0 Acknowledgements**

This document contains information from the Study of Osteoporotic Fractures (SOF), the Health and Bone Composition study (Health ABC), the Bureau of Labor Statistics (BLS) and the Physical Activity Scale for the Elderly. The PASE material is copy righted, © 1991 New England Research Institute.