Supplemental Appendix 1. Instrument - Autonomic Symptom Profile

1. In the past year, have you ever felt faint, dizzy, or "goofy" or had difficulty thinking soon after standing up from a sitting or lying down position?
   1. Yes
   2. No - *If you marked No, go to question 20.*

1. When standing up, how frequently do you get these feelings or symptoms?
   1. Rarely
   2. Occasionally
   3. Frequently
   4. Almost always

1. How would you rate the severity of these feelings or symptoms?
   1. Mild
   2. Moderate
   3. Severe

1. For how long have you been experiencing these feelings or symptoms?
   1. Less than 3 months
   2. 3 to 6 months
   3. 7 to 12 months
   4. 13 months to 5 years
   5. More than 5 years
   6. As long as I can remember

1. In the past year, how often have you ended up fainting soon after standing up from a sitting or lying down position?
   1. Never
   2. Once
   3. Twice
   4. Three times 4 Four times

5 Five or more times

1. How cautious are you about standing up from a sitting or lying down position?
   1. Not cautious at all
   2. Somewhat cautious
   3. Extremely cautious

1. What part of the day are these feelings worse? *(Check only one)*
   1. Early morning
   2. Rest of morning
   3. Afternoon
   4. Evening
   5. At night, when I get up after I’ve been asleep
   6. No particular time is worse
   7. Other time, specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. In the past year, have these feelings or symptoms that you have experienced:
   1. Gotten much worse
   2. Gotten somewhat worse
   3. Stayed about the same
   4. Gotten somewhat better
   5. Gotten much better
   6. Completely gone

Please rate the average severity you have experienced in the past year for each of the following symptoms.

Have Mild Moderate Severe

not had

1. Rapid or increased heart rate? 1 2 3 4

(palpitations)

1. Sickness to your stomach 1 2 3 4

(nausea) or vomiting?

1. A spinning or swimming 1 2 3 4 sensation?
2. Dizziness? 1 2 3 4
3. Blurred vision? 1 2 3 4
4. Feeling of weakness? 1 2 3 4
5. Feeling shaky or shaking 1 2 3 4 sensation?
6. Feeling anxious or nervous? 1 2 3 4
7. Turning pale 1 2 3 4
8. Clammy feeling to your skin? 1 2 3 4

1. Do you have any biologic (blood, natural) relatives among your parents, grandparents, brothers, sisters, or children who have frequent dizziness after standing from a sitting or lying down position?
   1. Yes – *if Yes, please list their names and relationship to you*
   2. No

Name/Relationship

* 1. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
  2. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
  3. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
  4. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

In the past year, have you ever felt faint, dizzy, or "goofy" or had difficulty thinking:

Yes No

1. Soon after a meal? 1 2
2. After standing for a long time? 1 2
3. During or soon after physical activity or exercise? 1 2
4. During or soon after being in a hot bath, shower, tub, or 1 2 sauna?
5. Have you every felt dizzy or faint or actually fainted 1 2 when you saw blood or had a blood sample taken?

In the past year, have you fainted:

Yes No

1. While passing urine? 1 2
2. While coughing? 1 2
3. While pressing on the side of your neck? 1 2
4. Before a public speech? 1 2
5. Any other time? 1 2

*If you checked “Yes” to any of these questions on fainting, please describe circumstances below*

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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1. In the past year, have you ever completely lost consciousness after a spell of dizziness?
   1. Yes
   2. No

1. In the past year, have you had any seizures or convulsions?
   1. Yes
   2. No

In the past 5 years, how would you rate the amount of trouble, if any, you have had:

None Some A Lot Constant

1. With paralysis in part of your face? 1 2 3 4
2. With feeling of complete weakness 1 2 3 4 all over your body?
3. With attacks of uncontrollable 1 2 3 4 movements of your arms or legs?
4. With attacks in which you couldn’t 1 2 3 4

control your speech?

1. Have you ever in your life had a spell of dizziness?
   1. Yes
   2. No
2. In the past year, have you ever noticed color changes in your skin, such as red, white, or purple?
   1. Yes
   2. No – *if you marked No, go to question 48.*

What color changes have occurred? *(Check all that apply)*

1. □ My skin turns red
2. □ My skin turns white
3. □ My skin turns purple

41 □ Other, please specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

What parts of your body are affected by these color changes? *(Check all that apply)*

1. □ My hands
2. □ My feet
3. □ Other parts, please specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
4. □ Entire body

1. For how long have you been experiencing these changes in skin color?
   1. Less than 3 months
   2. 3 to 6 months
   3. 7 to 12 months
   4. 13 months to 5 years
   5. More than 5 years
   6. As long as I can remember

1. Are these changes in your skin color:
   1. Gotten much worse
   2. Gotten somewhat worse
   3. Stayed about the same
   4. Gotten somewhat better
   5. Gotten much better
   6. Completely gone

1. In the past year, after a long hot bath or shower, have you ever noticed the pads on the ends of your fingers wrinkle up?
   1. Yes
   2. No

1. In the past 5 years, what changes, if any, have occurred in your general body sweating?
   1. I sweat much more than I used to
   2. I sweat somewhat more than I used to
   3. I have not noticed any changes in my sweating
   4. I sweat somewhat less than I used to
   5. I sweat much less than I used to
2. In the past 5 years, what changes, if any, have occurred in the amount your feet sweat?
   1. They sweat much more than they used to
   2. They sweat somewhat more than I used to
   3. I haven't noticed any changes in my sweating
   4. They sweat somewhat less than I used to
   5. They sweat much less than I used to

1. In the past 5 years, what changes, if any, have occurred in facial sweating after eating spicy foods?
   1. I sweat much more than I used to
   2. I sweat somewhat more than I used to
   3. I have not noticed any changes in my sweating
   4. I sweat somewhat less than I used to
   5. I sweat much less than I used to
   6. I avoid eating spicy foods because I sweat so much
   7. I avoid eating spicy foods for other reasons

In the past 5 years, what changes, if any, have occurred in your ability to tolerate heat during a hot day, strenuous work or exercise, hot bath or shower, hot tub, or sauna? *(Check all that apply)*

1. □ I now get more overheated
2. □ I now get dizzy
3. □ I now get short of breath
4. □ Other changes, please specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
5. □ No change

1. Do your eyes feel excessively dry?
   1. Yes
   2. No

1. Does your mouth feel excessively dry?
   1. Yes
   2. No

1. Do you have excessive amounts of saliva formation?
   1. Yes
   2. No

1. What is the longest period of time that you have had any one of these symptoms: dry eyes, dry mouth, or increased saliva production?
   1. I have not had any of these symptoms
   2. Less than 3 months
   3. 3 to 6 months
   4. 7 to 12 months
   5. 13 months to 5 years
   6. More than 5 years
   7. As long as I can remember

1. For the symptom of dry eyes, dry mouth, or increased saliva production that you have had for the longest period of time, is this symptom:
   1. I have not had any of these symptoms
   2. Getting much worse
   3. Getting somewhat worse
   4. Staying about the same
   5. Getting somewhat better
   6. Getting much better
   7. Completely gone

1. What weight changes, if any, have you had over the past year?
   1. I have lost about \_\_\_\_\_\_\_\_\_\_ pounds
   2. My weight has not changed
   3. I have gained about \_\_\_\_\_\_\_\_\_\_ pounds

1. In the past year, have you noticed any changes in how quickly you get full when eating a meal?
   1. I get full a lot more quickly now than I used to
   2. I get full more quickly now than I used to
   3. I haven't noticed any change
   4. I get full less quickly now than I used to
   5. I get full a lot less quickly now than I used to

1. In the past year, have you felt excessively full or persistently full (bloated feeling) after a meal?
   1. Never
   2. Sometimes
   3. A lot of the time

1. In the past year, have you felt like you had a persistent upset stomach (nausea)?
   1. Never
   2. Sometimes
   3. A lot of the time

1. In the past year, have you vomited after a meal?
   1. Never
   2. Sometimes
   3. A lot of the time

1. In the past year, have you had a cramping or colicky abdominal pain?
   1. Never – *if never, go to question 70.*
   2. Sometimes
   3. A lot of the time

1. Are these pains usually after a meal?
   1. Yes
   2. No

1. How long have you had these cramping or colicky abdominal pains?
   1. Less than 3 months
   2. 3 to 6 months
   3. 7 to 12 months
   4. 13 months to 5 years
   5. More than 5 years
   6. As long as I can remember

1. In the past year, have you had any bouts of diarrhea?
   1. Yes
   2. No – *if you marked No, go to question 77.*

1. How frequently does this occur?
   1. Rarely
   2. Occasionally
   3. Frequently, \_\_\_\_\_\_\_\_\_\_\_ times per month
   4. Constantly

1. How severe are these bouts of diarrhea?
   1. Mild
   2. Moderate
   3. Severe

1. What part of the day do they seem to be worse?
   1. First thing in the morning
   2. Rest of the morning 3 Afternoon 4 Evening
   3. During the night
   4. No particular time

1. Do these bouts of diarrhea usually occur after meal?
   1. Yes
   2. No

1. Are these bouts of diarrhea accompanied with lots of rectal gas (flatus)?
   1. Never
   2. Occasionally
   3. Frequently
   4. Always
2. Are your bouts with diarrhea getting:
   1. Much worse
   2. Somewhat worse
   3. Staying the same
   4. Somewhat better 5 Much better

6 Completely gone

1. In the past year, have you been constipated?
   1. Yes
   2. No – *if you marked No, go to question 81.*

1. How frequently are you constipated?
   1. Rarely
   2. Occasionally
   3. Frequently, \_\_\_\_\_\_\_\_\_\_\_ times per month
   4. Constantly

1. How severe are these episodes of constipation?
   1. Mild
   2. Moderate
   3. Severe

1. Is your constipation getting:
   1. Much worse
   2. Somewhat worse
   3. Staying the same
   4. Somewhat better 5 Much better

6 Completely gone

1. Overall, are your abdominal symptoms of vomiting, diarrhea, constipation, or weight loss getting:
   1. I have not had these symptoms
   2. Much worse
   3. Somewhat worse
   4. Staying the same
   5. Somewhat better 5 Much better

6 Completely gone

1. Which one of the following symptoms has been most troublesome for you?

*(Check only one)*

* 1. None
  2. Vomiting
  3. Diarrhea
  4. Constipation
  5. Weight loss

1. How long have you had this most troublesome symptom?
   1. I do not have any of these symptoms
   2. Less than 3 months
   3. 3 to 6 months
   4. 7 to 12 months
   5. 13 months to 5 years
   6. More than 5 years
   7. As long as I can remember

1. Is this most troublesome symptom getting:
   1. I have not had these symptoms
   2. Much worse
   3. Somewhat worse
   4. Staying the same
   5. Somewhat better 5 Much better

6 Completely gone

1. In the past 5 years, how would you rate the amount of trouble, if any, you have had with difficulty in swallowing?
   1. No trouble
   2. Some trouble
   3. A lot of trouble
   4. Constant trouble

1. In the past 5 years, how would you rate the amount of trouble, if any, you have had with everything you eat tasting the same?
   1. No trouble
   2. Some trouble
   3. A lot of trouble
   4. Constant trouble

Have you ever in your life:

1. Been nauseated or vomited?
   1. Yes
   2. No

1. Had a bout of diarrhea?
   1. Yes
   2. No
2. Lost your appetite for at least part of a day?
   1. Yes
   2. No

1. Felt discomfort or pain in the pit of your stomach?
   1. Yes
   2. No

1. In the past year, have you ever lost control of your bladder function?
   1. Never
   2. Occasionally
   3. Frequently, \_\_\_\_\_\_\_\_\_\_\_ times per month
   4. Constantly

1. In the past year, have had difficulty passing urine?
   1. Never
   2. Occasionally
   3. Frequently, \_\_\_\_\_\_\_\_\_\_\_ times per month
   4. Constantly

1. In the past year, have you had trouble completely emptying your bladder?
   1. Never
   2. Occasionally
   3. Frequently, \_\_\_\_\_\_\_\_\_\_\_ times per month
   4. Constantly

1. How would you describe your current sexual desire?
   1. Completely absent
   2. Greatly reduced
   3. Somewhat reduced
   4. About the same or more than in the past

*If male, please complete questions 95 – 106.*

*If female, please go to question 107.*

1. Are you able to have a full erection?
   1. Never under any circumstances
   2. Much less frequently than in the past
   3. Somewhat less frequently than in the past
   4. The same or more frequently than in the past

Which of the following statements apply to your situation? *(Check all that apply)*

1. □ My ability to have intercourse has not changed
2. □ I have erections but am unable to have intercourse
3. □ I can have intercourse only some of the time
4. □ My erections are definitely impaired
5. □ I am able to have intercourse, but am unable to ejaculate
6. □ I have "dry orgasms" and afterward my urine looks milky
7. □ I have been unable to have erections or they have been impaired

since I started taking a medication called \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. □ Other situation, please describe \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. □ None of the above apply

1. How long have you had difficulty with erectile function?
   1. I do not have this difficulty
   2. Less than 3 months
   3. 3 to 6 months
   4. 7 to 12 months
   5. 13 months to 5 years
   6. More than 5 years
   7. As long as I can remember

1. Is this difficulty getting:
   1. I have not had this difficulty
   2. Much worse
   3. Somewhat worse
   4. Staying the same
   5. Somewhat better 5 Much better

6 Completely gone

1. In the past year, without sunglasses or tinted glasses, has bright light bothered your eyes?
   1. Never
   2. Occasionally
   3. Frequently
   4. Constantly

1. How severe is this sensitivity to bright light?
   1. Mild
   2. Moderate
   3. Severe

1. In the past year, have you had trouble focusing your eyes?
   1. Never
   2. Occasionally
   3. Frequently
   4. Constantly

1. How severe is this focusing problem?
   1. Mild
   2. Moderate
   3. Severe

1. In the past year, have you had blurred vision?
   1. Never
   2. Occasionally
   3. Frequently
   4. Constantly

1. How severe is this blurred vision problem?
   1. Mild
   2. Moderate
   3. Severe

1. In the past year, have you had difficulty seeing at night?
   1. Never
   2. Occasionally
   3. Frequently
   4. Constantly

1. How severe is this difficulty seeing at night
   1. Mild
   2. Moderate
   3. Severe

1. In the past year, has the same degree of light seemed:
   1. Excessively dimmer
   2. Much dimmer
   3. About the same
   4. Much brighter
   5. Excessively brighter

1. Which one of the following eye symptoms is the most troublesome for you?
   1. None
   2. Trouble focusing 2 Blurred vision

3 Difficulty seeing at night

1. How long have you had this most troublesome eye symptom?
   1. I do not have any of these symptoms
   2. Less than 3 months
   3. 3 to 6 months
   4. 7 to 12 months
   5. 13 months to 5 years
   6. More than 5 years
   7. As long as I can remember
2. Is this most troublesome symptom with your eyes getting:
   1. I do not have any of these symptoms
   2. Much worse
   3. Somewhat worse
   4. Staying the same
   5. Somewhat better 5 Much better

6 Completely gone

1. In the past year, have you ever noticed or been told that while sleeping you stop breathing for several seconds?
   1. Yes
   2. No

1. In the past year, have you ever noticed or been told that while sleeping you snore loudly?
   1. Yes
   2. No

Have you ever been told you have or been diagnosed as having: 121. Narcolepsy?

* 1. Yes
  2. No
  3. Do not know

1. Obstructive sleep apnea?
   1. Yes
   2. No
   3. Do not know

1. Abnormal or disordered sleep patterns?
   1. Yes
   2. No
   3. Do not know

1. Currently, how refreshing and restorative is your sleep?
   1. Not at all restorative - derive no benefit
   2. Some slight restorative value
   3. Restorative, but not adequate
   4. Relatively satisfactory
   5. Very satisfactory - feel completely refreshed

1. Compared with a year ago, how would you rate your own sleep over the last month?
   1. Last month was much worse than a year ago
   2. Last month was slightly worse than a year ago
   3. Last month was about the same as a year ago
   4. Last month was slightly better than a year ago
   5. Last month was much better than a year ago

1. Have you ever in your life had difficulty getting to sleep or staying asleep once you were asleep?
   1. Yes
   2. No

1. In the past year, have you ever noticed or been told that during the day you sometimes breathe very loudly (i.e. croup)?
   1. Yes
   2. No

How would you describe your alcohol use over the past year? *(Check all that apply)*

1. □ I have not drank any alcohol over the past year
2. □ I drink socially only
3. □ I have used alcohol excessively in the past year
4. □ I have been intoxicated one or more times in the past year
5. □ I have passed out from drinking too much alcohol one or more times in the past year

How would you describe your drug use over the past year? *(Check all that apply)*

1. □ I have not used drugs over the past year
2. □ I have used drugs excessively in the past year
3. □ I have been high one or more times in the past year
4. □ I have passed out from using drugs one or more times in the past year

1. Have you ever felt that you have used alcohol or drugs excessively?
   1. Yes
   2. No

1. Have you ever been told you have or been diagnosed as having alcohol or drug dependency?
   1. Yes
   2. No

1. Have you ever received treatment for alcohol or other drug dependency?
   1. Yes
   2. No

*If Yes, please list the drugs involved including alcohol*

* 1. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
  2. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
  3. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
  4. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Which of the following describe your cigarette smoking? *(Check all that apply)*

1. □ I have never smoked cigarettes
2. □ I have smoked cigarettes in the past but have stopped:
3. Date Quit: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
4. □ I am currently smoking
5. Cigarettes per day \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. In the past 5 years, how would you rate the amount of trouble, if any, you have had with over sensitive hearing?
   1. None
   2. Some
   3. A lot
   4. Constant

1. Have you ever in your life had difficulty keeping your mind on your job or task?
   1. Yes
   2. No

|  |  |  |
| --- | --- | --- |
| What medications have you taken in the past month? | |  |
| How often do you | | How much do you take each time? |
| Name of Medication | take it? |
| \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
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We welcome below any comments you might have about what might have caused or been associated with your current illness or anything that might be helpful to us in understanding your current conditions.

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Comment: The original ASP consisted of 167 questions. In this updated version, demographic questions (1-17) were eliminated. Responses to questions that could exceed the integer value of 9 were originally assigned more than one “answer” (i.e. “1” and “3” for “13”); this has been condensed to one answer resulting in further reduction of the number of questions by four. The result is a questionnaire with 146 questions. The last two questions concerning medications and comments are not numbered.