

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.*

2. When standing up, how frequently do you get these feelings or symptoms?

- 1 Rarely
- 2 Occasionally
- 3 Frequently
- 4 Almost always

3. How would you rate the severity of these feelings or symptoms?

- 1 Mild
- 2 Moderate
- 3 Severe

4. 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

5. In the past year, how often have you ended up fainting soon after standing up from a sitting or lying down position?

- 0 Never
- 1 Once
- 2 Twice
- 3 Three times
- 4 Four times
- 5 Five or more times

6. 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

7. 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 _____

8. 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 not had	Mild	Moderate	Severe
9.	Rapid or increased heart rate? (palpitations)	1	2	3	4
10.	Sickness to your stomach (nausea) or vomiting?	1	2	3	4
11.	A spinning or swimming sensation?	1	2	3	4
12.	Dizziness?	1	2	3	4
13.	Blurred vision?	1	2	3	4
14.	Feeling of weakness?	1	2	3	4
15.	Feeling shaky or shaking sensation?	1	2	3	4
16.	Feeling anxious or nervous?	1	2	3	4
17.	Turning pale	1	2	3	4
18.	Clammy feeling to your skin?	1	2	3	4

19. 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

- | | | | |
|-----|--|---|---|
| 20. | Soon after a meal? | 1 | 2 |
| 21. | After standing for a long time? | 1 | 2 |
| 22. | During or soon after physical activity or exercise? | 1 | 2 |
| 23. | During or soon after being in a hot bath, shower, tub, or sauna? | 1 | 2 |
| 24. | Have you every felt dizzy or faint or actually fainted when you saw blood or had a blood sample taken? | 1 | 2 |

In the past year, have you fainted:

- | | | Yes | No |
|-----|--|-----|----|
| 25. | While passing urine? | 1 | 2 |
| 26. | While coughing? | 1 | 2 |
| 27. | While pressing on the side of your neck? | 1 | 2 |
| 28. | Before a public speech? | 1 | 2 |
| 29. | Any other time? | 1 | 2 |

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

30. In the past year, have you ever completely lost consciousness after a spell of dizziness?

- 1 Yes
2 No

31. 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 | |
|-----|--|------|-------|----------|---|
| 32. | With paralysis in part of your face? | 1 | 2 | 3 | 4 |
| 33. | With feeling of complete weakness all over your body? | 1 | 2 | 3 | 4 |
| 34. | With attacks of uncontrollable movements of your arms or legs? | 1 | 2 | 3 | 4 |
| 35. | With attacks in which you couldn't control your speech? | 1 | 2 | 3 | 4 |

36. Have you ever in your life had a spell of dizziness?

- 1 Yes
2 No

37. 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)

38. My skin turns red
39. My skin turns white
40. My skin turns purple
41. Other, please specify _____

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

42. My hands
43. My feet
44. Other parts, please specify _____
45. Entire body

46. 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

47. 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

48. 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

49. 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

50. 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

51. 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*)

- 52. I now get more overheated
- 53. I now get dizzy
- 54. I now get short of breath
- 55. Other changes, please specify _____
- 56. No change

57. Do your eyes feel excessively dry?

- 1 Yes
- 2 No

58. Does your mouth feel excessively dry?

- 1 Yes
- 2 No

59. Do you have excessive amounts of saliva formation?

- 1 Yes
- 2 No

60. What is the longest period of time that you have had any one of these symptoms: dry eyes, dry mouth, or increased saliva production?

- 0 I have not had any of these 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

61. 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:

- 0 I have not had any of these symptoms
- 1 Getting much worse
- 2 Getting somewhat worse
- 3 Staying about the same
- 4 Getting somewhat better
- 5 Getting much better
- 6 Completely gone

62. 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

63. 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

64. 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

65. 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

66. In the past year, have you vomited after a meal?

- 1 Never
- 2 Sometimes
- 3 A lot of the time

67. 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

68. Are these pains usually after a meal?

- 1 Yes
- 2 No

69. 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

70. In the past year, have you had any bouts of diarrhea?

- 1 Yes
- 2 No – *if you marked No, go to question 77.*

71. How frequently does this occur?

- 1 Rarely
- 2 Occasionally
- 3 Frequently, _____ times per month
- 4 Constantly

72. How severe are these bouts of diarrhea?

- 1 Mild
- 2 Moderate
- 3 Severe

73. 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
- 5 During the night
- 6 No particular time

74. Do these bouts of diarrhea usually occur after meal?

- 1 Yes
- 2 No

75. Are these bouts of diarrhea accompanied with lots of rectal gas (flatus)?

- 1 Never
- 2 Occasionally
- 3 Frequently

4 Always

76. 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

77. In the past year, have you been constipated?

- 1 Yes
- 2 No – *if you marked No, go to question 81.*

78. How frequently are you constipated?

- 1 Rarely
- 2 Occasionally
- 3 Frequently, _____ times per month
- 4 Constantly

79. How severe are these episodes of constipation?

- 1 Mild
- 2 Moderate
- 3 Severe

80. Is your constipation getting:

- 1 Much worse
- 2 Somewhat worse
- 3 Staying the same
- 4 Somewhat better
- 5 Much better
- 6 Completely gone

81. Overall, are your abdominal symptoms of vomiting, diarrhea, constipation, or weight loss getting:

- 0 I have not had these symptoms
- 1 Much worse
- 2 Somewhat worse
- 3 Staying the same
- 4 Somewhat better
- 5 Much better
- 6 Completely gone

82. Which one of the following symptoms has been most troublesome for you?
(*Check only one*)

- 0 None

- 1 Vomiting
- 2 Diarrhea
- 3 Constipation
- 4 Weight loss

83. How long have you had this most troublesome symptom?

- 0 I do not have any of these 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

84. Is this most troublesome symptom getting:

- 0 I have not had these symptoms
- 1 Much worse
- 2 Somewhat worse
- 3 Staying the same
- 4 Somewhat better
- 5 Much better
- 6 Completely gone

85. 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

86. 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:

87. Been nauseated or vomited?

- 1 Yes
- 2 No

88. Had a bout of diarrhea?

- 1 Yes
- 2 No

89. Lost your appetite for at least part of a day?

- 1 Yes
- 2 No

90. Felt discomfort or pain in the pit of your stomach?

- 1 Yes
- 2 No

91. In the past year, have you ever lost control of your bladder function?

- 1 Never
- 2 Occasionally
- 3 Frequently, _____ times per month
- 4 Constantly

92. In the past year, have had difficulty passing urine?

- 1 Never
- 2 Occasionally
- 3 Frequently, _____ times per month
- 4 Constantly

93. In the past year, have you had trouble completely emptying your bladder?

- 1 Never
- 2 Occasionally
- 3 Frequently, _____ times per month
- 4 Constantly

94. 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.

95. 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)*

- 96. My ability to have intercourse has not changed
- 97. I have erections but am unable to have intercourse
- 98. I can have intercourse only some of the time
- 99. My erections are definitely impaired

100. I am able to have intercourse, but am unable to ejaculate
101. I have "dry orgasms" and afterward my urine looks milky
102. I have been unable to have erections or they have been impaired since I started taking a medication called _____
103. Other situation, please describe _____
104. None of the above apply

105. How long have you had difficulty with erectile function?

- 0 I do not have this difficulty
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

106. Is this difficulty getting:

- 0 I have not had this difficulty
1 Much worse
2 Somewhat worse
3 Staying the same
4 Somewhat better
5 Much better
6 Completely gone

107. In the past year, without sunglasses or tinted glasses, has bright light bothered your eyes?

- 1 Never
2 Occasionally
3 Frequently
4 Constantly

108. How severe is this sensitivity to bright light?

- 1 Mild
2 Moderate
3 Severe

109. In the past year, have you had trouble focusing your eyes?

- 1 Never
2 Occasionally
3 Frequently
4 Constantly

110. How severe is this focusing problem?

- 1 Mild
2 Moderate

3 Severe

111. In the past year, have you had blurred vision?

- 1 Never
- 2 Occasionally
- 3 Frequently
- 4 Constantly

112. How severe is this blurred vision problem?

- 1 Mild
- 2 Moderate
- 3 Severe

113. In the past year, have you had difficulty seeing at night?

- 1 Never
- 2 Occasionally
- 3 Frequently
- 4 Constantly

114. How severe is this difficulty seeing at night

- 1 Mild
- 2 Moderate
- 3 Severe

115. 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

116. Which one of the following eye symptoms is the most troublesome for you?

- 0 None
- 1 Trouble focusing
- 2 Blurred vision
- 3 Difficulty seeing at night

117. How long have you had this most troublesome eye symptom?

- 0 I do not have any of these 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

118. Is this most troublesome symptom with your eyes getting:

- 0 I do not have any of these symptoms
- 1 Much worse
- 2 Somewhat worse
- 3 Staying the same
- 4 Somewhat better
- 5 Much better
- 6 Completely gone

119. In the past year, have you ever noticed or been told that while sleeping you stop breathing for several seconds?

- 1 Yes
- 2 No

120. 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

122. Obstructive sleep apnea?

- 1 Yes
- 2 No
- 3 Do not know

123. Abnormal or disordered sleep patterns?

- 1 Yes
- 2 No
- 3 Do not know

124. 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

125. 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

126. Have you ever in your life had difficulty getting to sleep or staying asleep once you were asleep?

- 1 Yes
- 2 No

127. 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*)

- 128. I have not drank any alcohol over the past year
- 129. I drink socially only
- 130. I have used alcohol excessively in the past year
- 131. I have been intoxicated one or more times in the past year
- 132. 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*)

- 133. I have not used drugs over the past year
- 134. I have used drugs excessively in the past year
- 135. I have been high one or more times in the past year
- 136. I have passed out from using drugs one or more times in the past year

137. Have you ever felt that you have used alcohol or drugs excessively?

- 1 Yes
- 2 No

138. Have you ever been told you have or been diagnosed as having alcohol or drug dependency?

- 1 Yes
- 2 No

139. 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*)

- 140. I have never smoked cigarettes
- 141. I have smoked cigarettes in the past but have stopped:
- 142. Date Quit: _____
- 143. I am currently smoking
- 144. Cigarettes per day _____

145. 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

146. 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?

Name of Medication	How often do you take it?	How much do you take each time?
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

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.

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.