The ANCA-associated Vasculitis Patient-Reported Outcome (AAV-PRO) Questionnaire

### **AAV-PRO Questionnaire**

#### **Symptoms**

### Due to having vasculitis or its treatment, please rate your experience of the following problems, in general, during the <u>past 4 weeks</u>.

		None	Very mild	Mild	Moderate	Severe
1.	Chest problems (such as wheezing, 'chest tightness', coughing, or shortness of breath)					
2.	Problems with your ears (such as pain, difficulty hearing, a sense of pressure, or blockage)					
3.	Problems with your eyes (such as pain, blurred or poor vision, or sensitivity to light)					
4.	Problems with your nose or sinuses (such as pain, a sense of pressure, nosebleeds, blockage, runny nose, or crusting)					
5.	Problems with your mouth or throat (such as dryness, mouth sores, hoarseness, sore throat, or difficulty eating/swallowing)					
6.	Problems with your joints (such as aches and pains or swelling)					
7.	Pain, cramps or weakness affecting your muscles					
8.	Problems with your skin (such as swelling, blotches, a rash, bruising, or lumps)					
9.	Tiredness or fatigue					
10.	Feeling uncomfortably hot, cold, or feverish					
11.	Indigestion, heartburn, nausea, or sickness (vomiting)					

Please ✓ only one box for each statement.

#### Difficulties with everyday life

## Due to having vasculitis or its treatment, how difficult have you found the following activities, in general, during the <u>past 4 weeks</u>?

		No difficulty	A little difficult	Moderately difficult	Extremely difficult	l could not do this
12.	Walking around shops for <u>at least</u> an hour					
13.	Walking up a flight of stairs					
14.	Doing the physical activities that you wanted to (such as walking, sports, or fitness classes)					
15.	Washing and drying yourself, or getting dressed, <u>without help</u> from another person					
16.	Getting enough good sleep					

Please ✓ only one box for each statement.

#### Social and emotional impact

# Due to having vasculitis or its treatment, how often have the following applied to you, in general, during the <u>past 4 weeks</u>?

		Please ✓ only one box for each statement.					
		None of the time	Rarely	Sometimes	Often	All of the time	
17.	I have felt concerned about my weight (weight gain or weight loss)						
18.	I have felt upset or frustrated because I have been unable to work or do my everyday tasks						

#### Social and emotional impact (continued)

### Due to having vasculitis or its treatment, how often have the following applied to you, in general, during the <u>past 4 weeks</u>?

		Please ✓ only one box for each statement.				
		None of the time	Rarely	Sometimes	Often	All of the time
19.	I have worried about what will happen to me in the future					
20.	I have been anxious, worried or stressed					
21.	I have had difficulty concentrating or being focussed					
22.	I have felt down or depressed					
23.	I have worried about being dependent on other people					
24.	I have had difficulty making <u>long-</u> <u>term</u> plans (for example, plans involving work, close relationships, or family)					
25.	I have worried about travelling a long distance from home					
26.	I have felt embarrassed or self- conscious due to my appearance or symptoms					
27.	I have felt that I have let other people down (for example, because you couldn't provide help, or had to cancel an arrangement)					
28.	I have felt that my life is now focussed on coping with my condition					
29.	I have worried about the long- term effects of treatment					