

1 **Supplementary Material**

2 **Supplementary Table 1: Main survey questions used in this**
3 **manuscript**

	Question	Answer
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8	Age	What was your age in years when the formal diagnosis was made? This was your age when first told you were extremely likely to have or definitely had sarcoidosis.
9		Separate choices
10	Ethnicity	Ethnicity Hispanic or Latino
11		Tick box
12	Race	American Indian/Alaska native, Asian, Black/African American, Native Hawaiian/Other Pacific Islander, White, some other race and prefer not to answer
13		Tick box
14		
15	Insurance	If you have health insurance or a health care plan, what type of health insurance do you currently have?
16		Select all that apply
17		
18	Education	If you are 18 years or older, what is the highest grade or level of school you completed?
19		Separate choices
20	Income	What is the annual gross income for the household in which you live (in U.S. dollars)?
21		Separate choices
22	Health care providers	What kind of health care provider(s) did you see for the symptoms BEFORE a diagnosis was made?
23		Select all that apply
24	Family history of sarcoidosis	Which family members also are known to have sarcoidosis?
25		Select all that apply
26	Sarcoidosis related admissions	Have you ever been admitted to the hospital for your sarcoidosis (Not for diagnostic procedures)?
27		Yes/no
28		
29	Sarcoidosis-specific therapy	Have you EVER taken medications for sarcoidosis? If Yes, indicate the status of each of the following medications.
30		Separate choices (completed treatment, have not had this treatment, have not taken medication, never worked, side effects/complications, still using this treatment, stopped working and unsure)
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35	Organ involvement	What organs have been diagnosed with sarcoidosis by a medical provider?
36		Select all that apply/ diagnosed, suspected, not involved and unsure
37		
38	Endocrine disorders	Have any of the following endocrine conditions been diagnosed by a physician?
39		Select all that apply
	Comorbidities	Have you developed any of the following disorders AFTER you were given the diagnosis of sarcoidosis?
		Select all that apply
	Use of antidepressants	What other medications have you been prescribed for the effects of sarcoidosis and the treatment of side effects (such as anxiety, sleep difficulties, osteoporosis and fatigue)? - Antidepressant or antidepressant/anti-anxiety medications such as citalopram (Celexa), fluoxetine (Prozac), escitalopram (Lexapro), fluvoxamine (Luvox), duloxetine (Cymbalta), venlafaxine (Effexor), paroxetine (Paxil), sertraline (Zoloft)
		(Select all that apply.)
	Feeling depressed	Do you feel depressed?
		Tick box (unsure, never, rarely, sometimes, often and always)
	Feeling tired	How often do you feel tired?
		Tick box (unsure, never, rarely, sometimes, often and always)
	Use of mobility assistive device	Do you use any type of medical or assistive device(s) to help you move around, communicate, or do things?
		Select all that apply
	Employment based disability	What is your employment status?
		Select all that apply
	Missing work days	How many days of work did you miss due to the diagnosis in the last 12 months?
		Separate choices
	Sarcoid related job termination	Have you needed to end your job due to health effects from sarcoidosis?
		Yes/No