



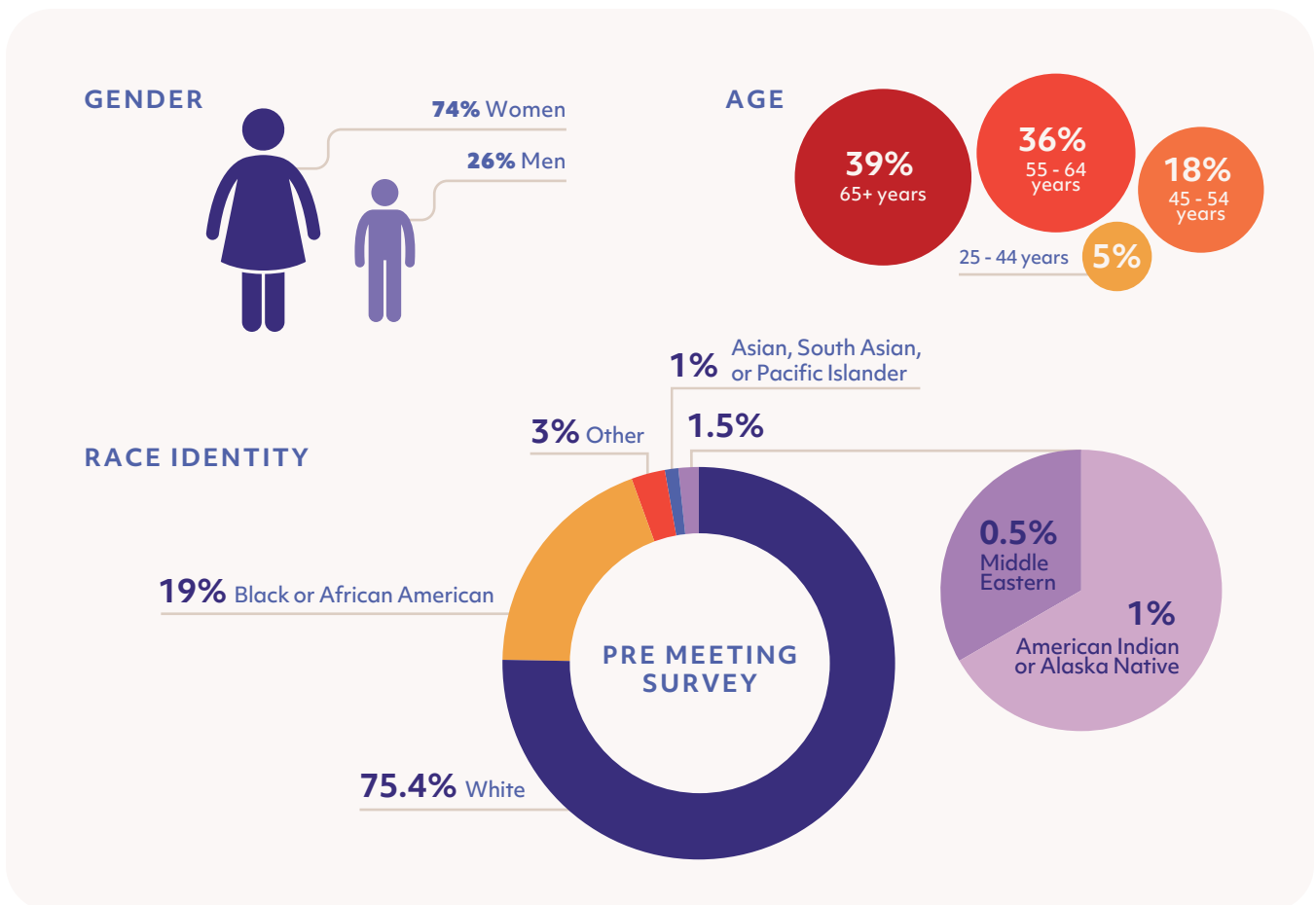
# Voice of the Patient

## EL-PFDD Planning Survey

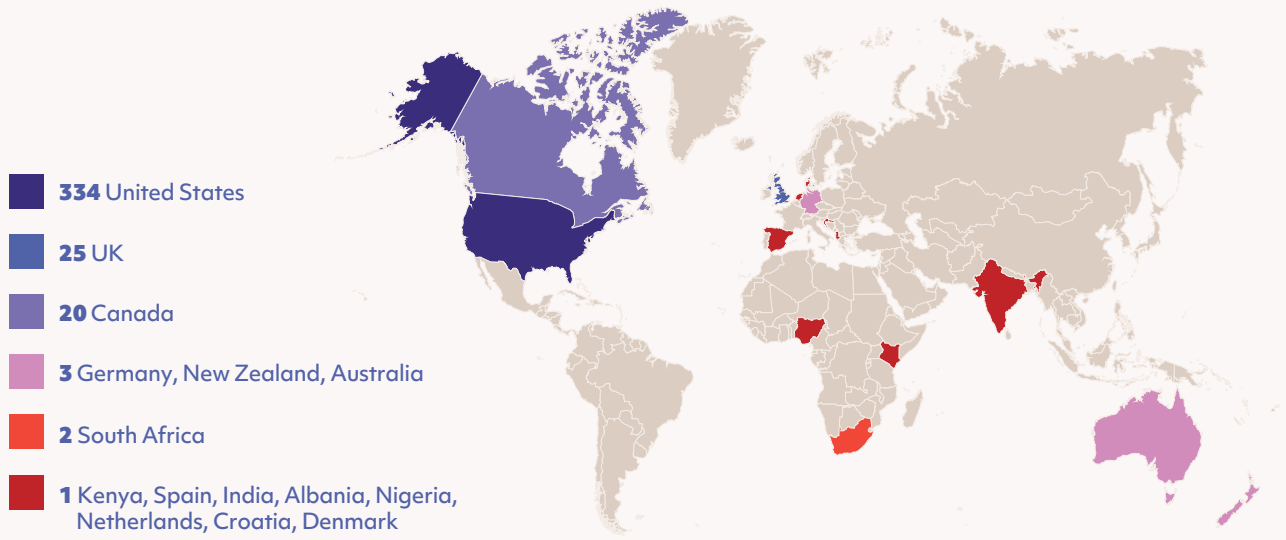
The EL-PFDD planning survey was conducted to capture the perspectives of people living with sarcoidosis and their caregivers, in order to guide the focus of the EL-PFDD meeting. The following section presents the survey results.

### 1. Demographics

- Total of 403 respondents
- Ages: 18-65+ years old
  - Most respondents were 65+ (157), followed by 55-64 (146). There were very few younger respondents, with only 1% between 25-34 and only 1 under 24.
- 6.7% of respondents were veterans



## GEOGRAPHIC DISTRIBUTION OF RESPONDENTS

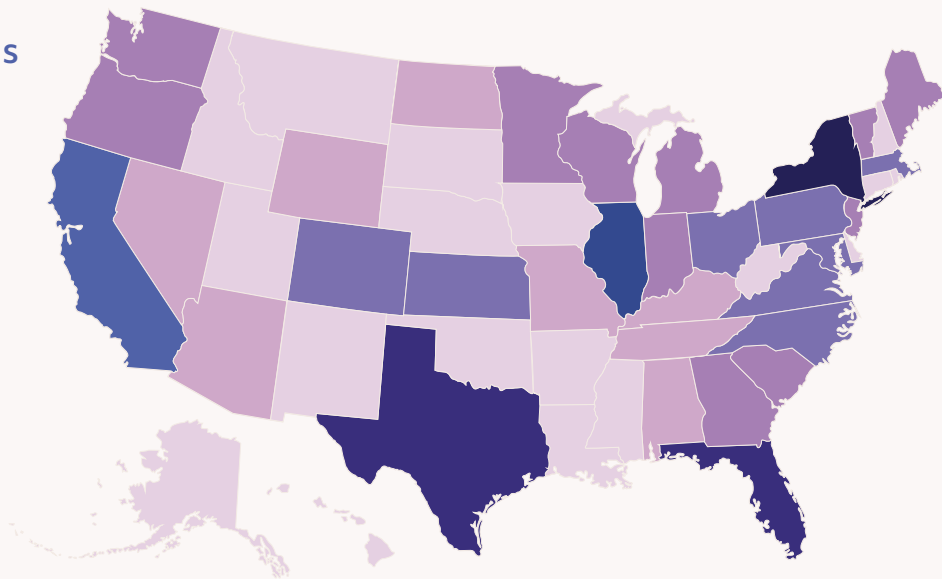


Notably, 46 of 50 US states were represented in the survey:

## GEOGRAPHIC DISTRIBUTION OF RESPONDENTS WITHIN THE U.S.

### TOP 5 U.S. STATES

New York	8%
Texas	7%
Florida	7%
Illinois	6%
California	5%

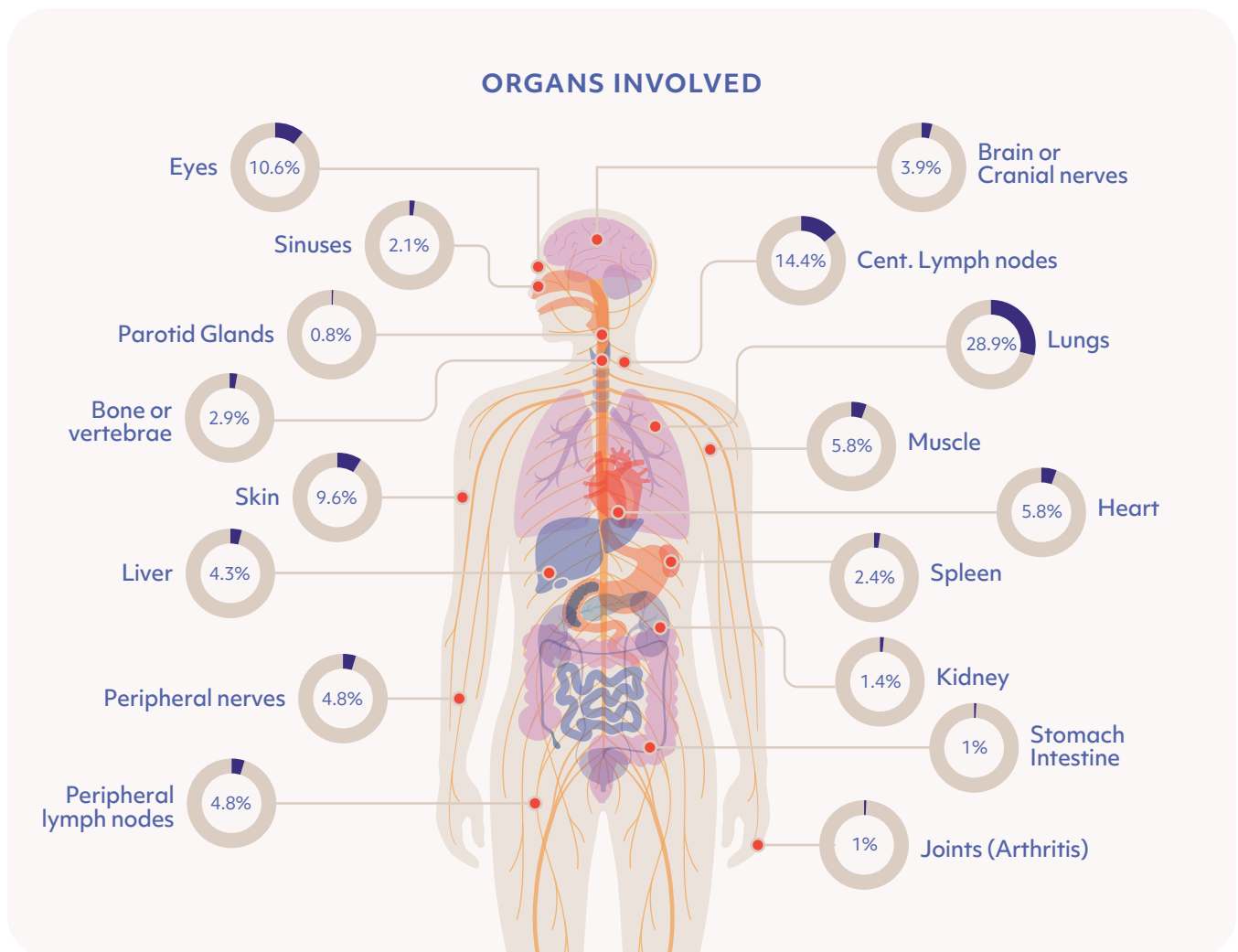
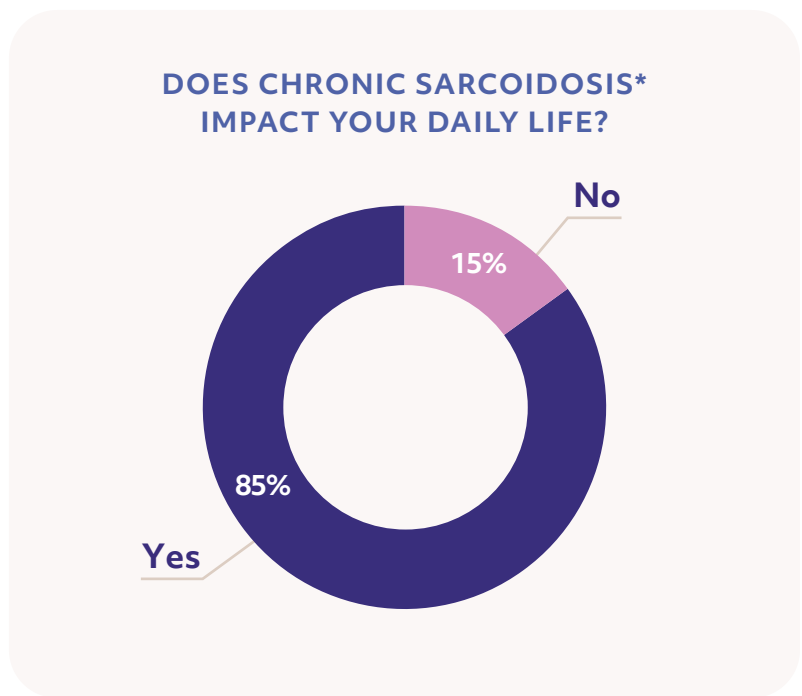


## 2. Diagnosis and Impact

- Most respondents were formally diagnosed between ages 46-60 (176)
- Least commonly diagnosed age ranges were 5-15 (3) and 76+ (3) respectively

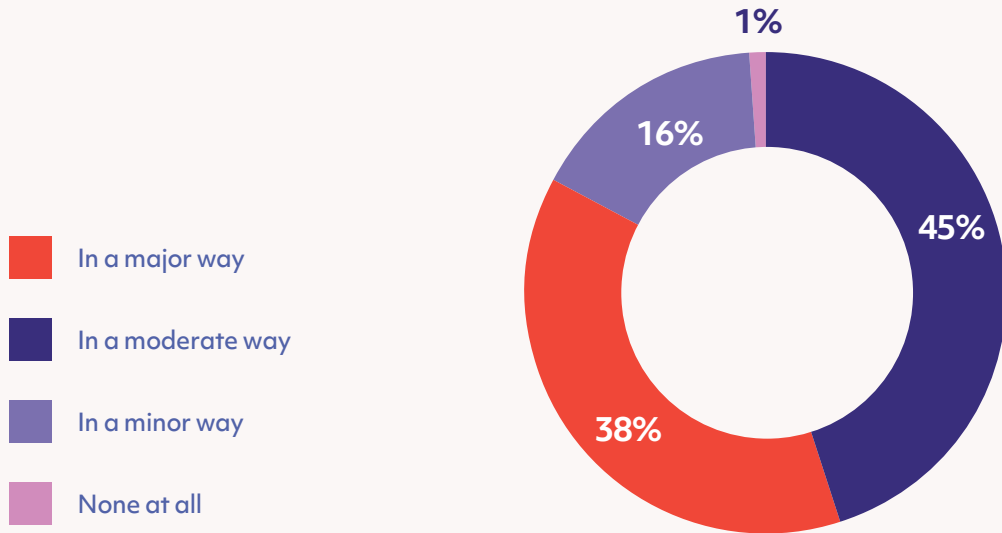
\* *chronic sarcoidosis:*  
lasting more than six months

The organs most impacted by sarcoidosis are the lungs, followed by the central lymph nodes, the joints, eyes, and skin. They are highlighted in the image below.

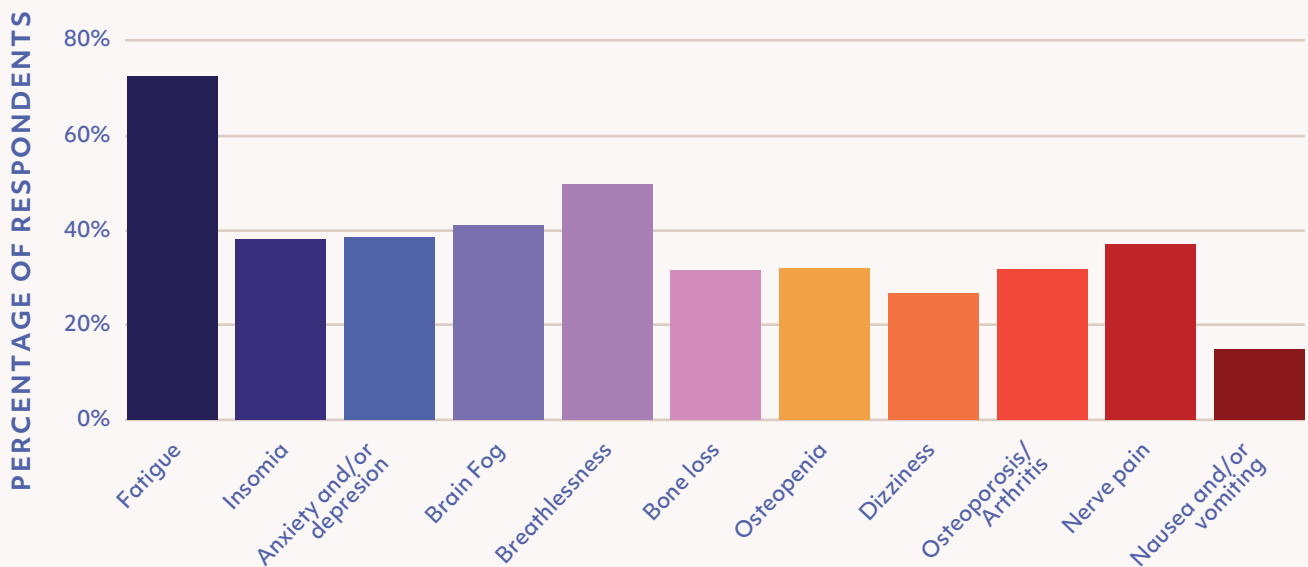


### 3. Symptom Impact

IN THE PAST 6 MONTHS, HOW MUCH HAVE YOUR SARCOIDOSIS SYMPTOMS AFFECTED YOUR DAILY LIFE?



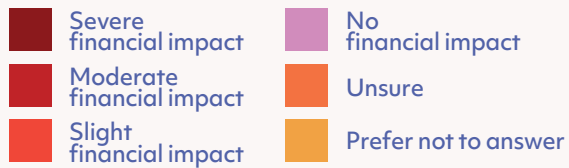
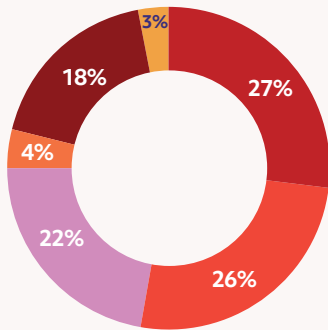
WHICH OF THE FOLLOWING SYMPTOMS HAVE MOST IMPACTED YOUR LIFE?



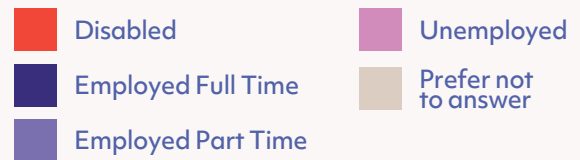
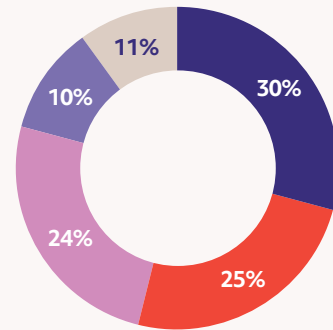
## 4. Employment Impact

29% of respondents said they had to terminate employment due to health effects from sarcoidosis  
*\*for those respondents who reported being employed*

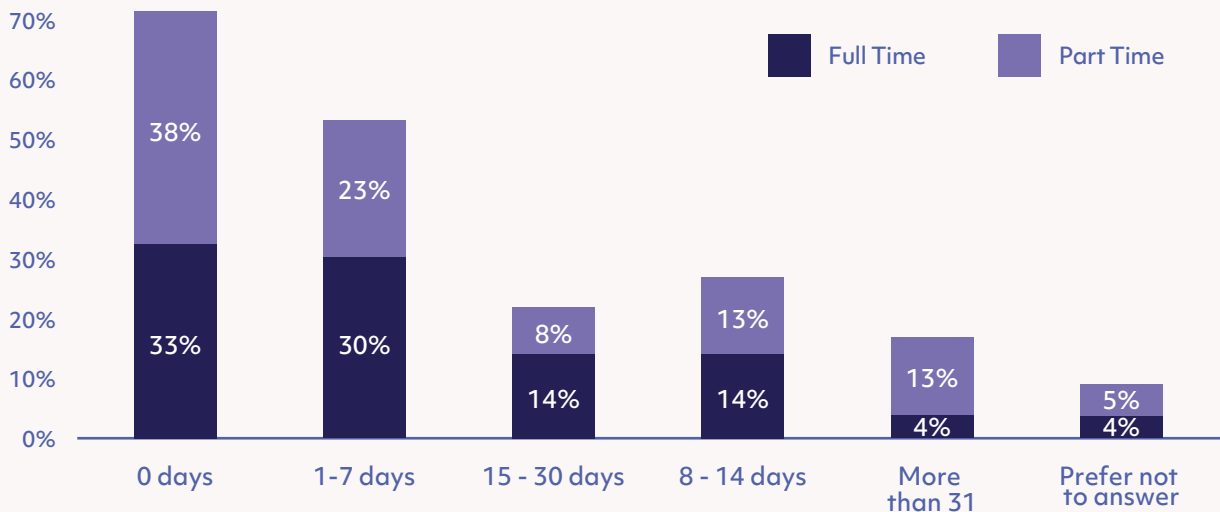
### EMPLOYMENT STATUS



### HOW HAS YOUR DIAGNOSIS AFFECTED YOUR FAMILY'S FINANCES?



### IN LAST 12 MONTHS, APPROXIMATELY HOW MANY DAYS OF WORK DID YOU MISS DUE TO SARCOIDOSIS?

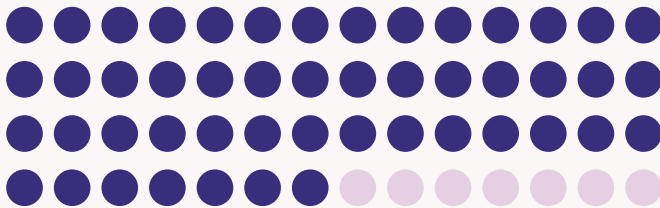


## 5. Experience with Medications

56%

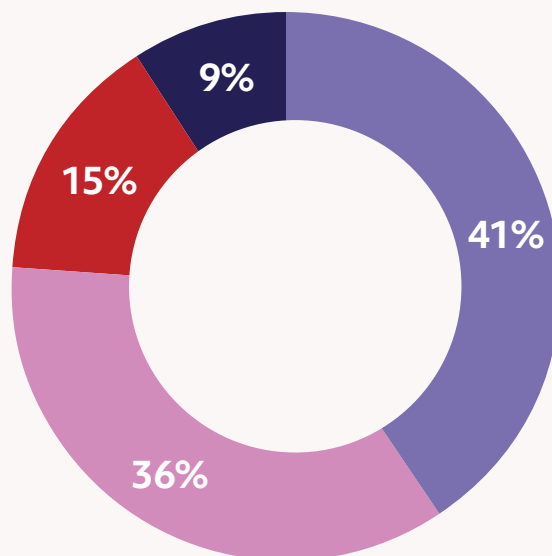
reported that the medications they have taken for sarcoidosis have caused side effects, other illnesses or permanent organ damage.

Of these group,



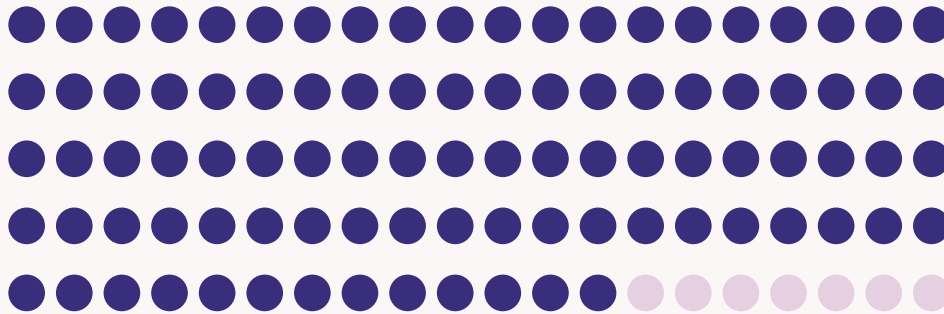
88% name steroids as the cause of these issues.

### MY THERAPIES FOR SARCOIDOSIS RELIEVE MY SYMPTOMS



Completely Moderately Slightly Not at all

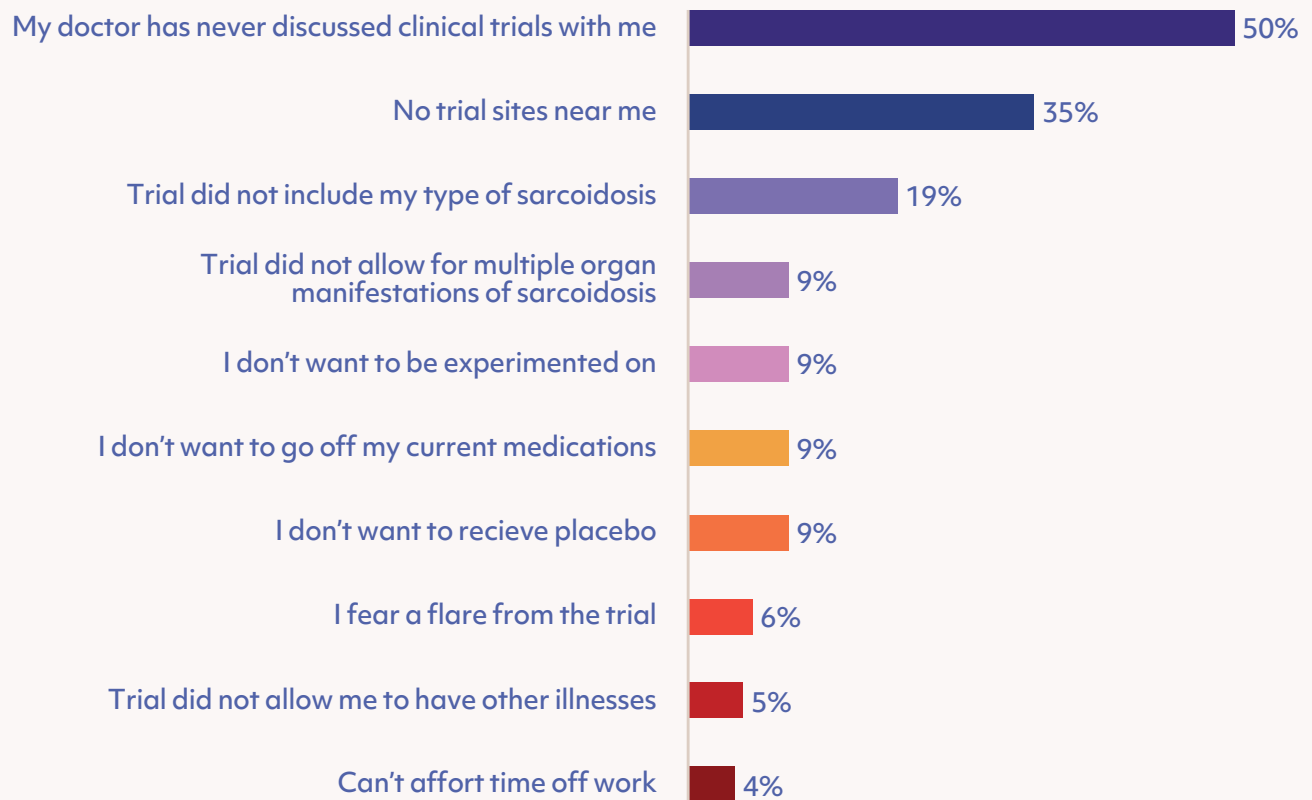
## 6. Clinical Trials



93%  
have participated  
in a clinical trial

For those who reported not having participated in a clinical trial, the question asked was:

### HAVE ANY OF THE FOLLOWING PREVENTED YOU FROM PARTICIPATING IN A CLINICAL TRIAL?



### WHAT WOULD MAKE YOU INTERESTED IN PARTICIPATING IN A CLINICAL TRIAL?

