

Introduction

- Sarcoidosis is a rare disease with an estimated incidence of between 4.7 and 64 per 100,000. Some 40% of individuals experience sarcoidosis as a chronic condition, while >60% of individuals find that the disease resolves within 2-5 years.
- However, it has been shown that patients can still have symptoms that result in a reduced quality of life even after clinical signs of disease have disappeared. These symptoms include fatigue, pain, everyday cognitive failure, small fibre neuropathy, exercise limitation and depressive symptoms.
- In 2016, a European Respiratory Society (ERS) Task Force (TF) was set up to develop an international clinical guideline on sarcoidosis treatment to provide evidence-based recommendations for healthcare professionals.
- Sarcoidosis outcomes are traditionally governed by clinical measures, such as blood tests, pulmonary function tests and imaging.
- The European Lung Foundation (ELF) supported the facilitation of patient input into the TF via its Sarcoidosis Patient Advisory Group (PAG), which comprises of patient organisation representatives from nine countries.

Purpose of Study

- Develop a survey designed to gather views about which treatment outcomes matter most to sarcoidosis patients with the results to inform the work of the TF.

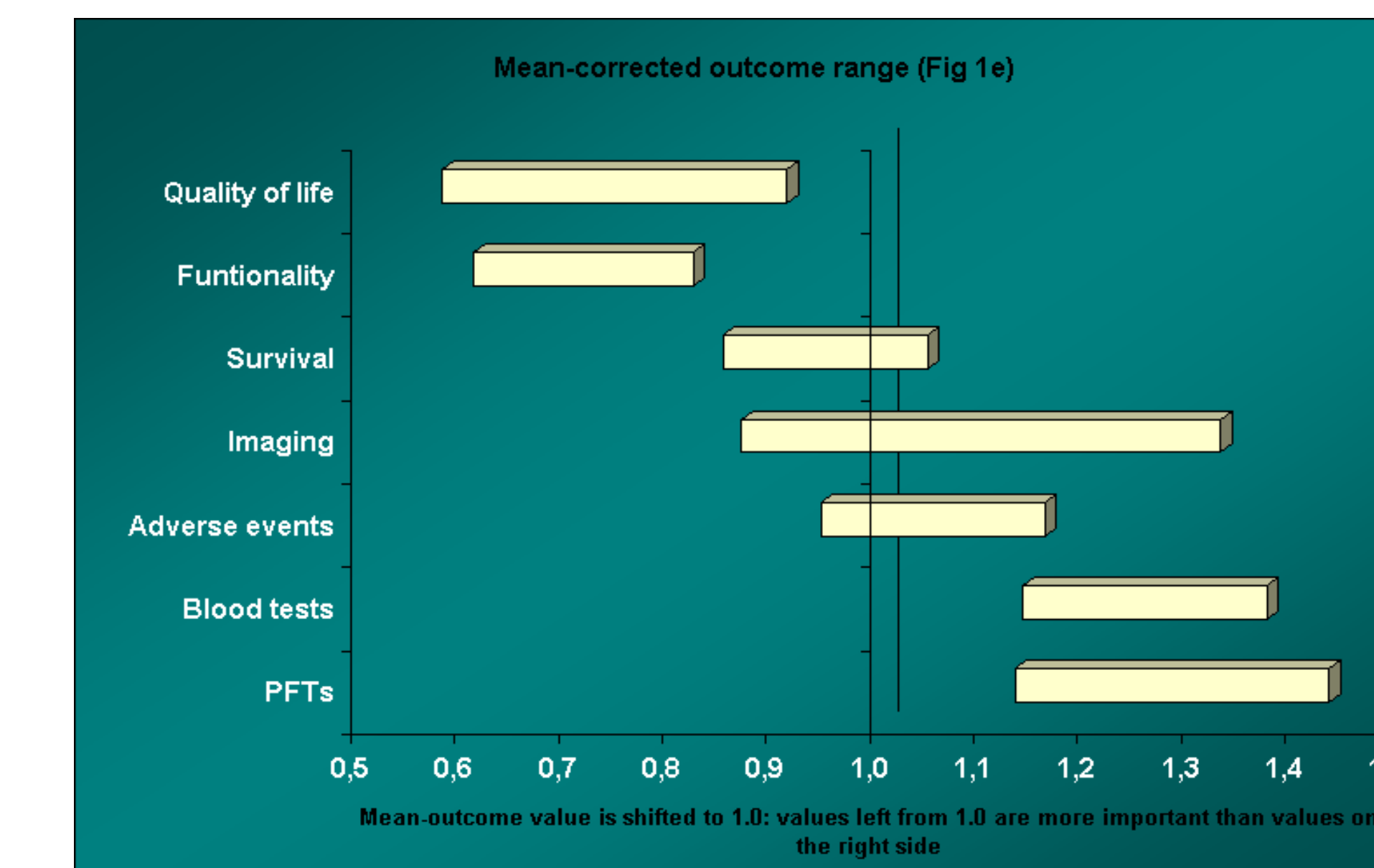
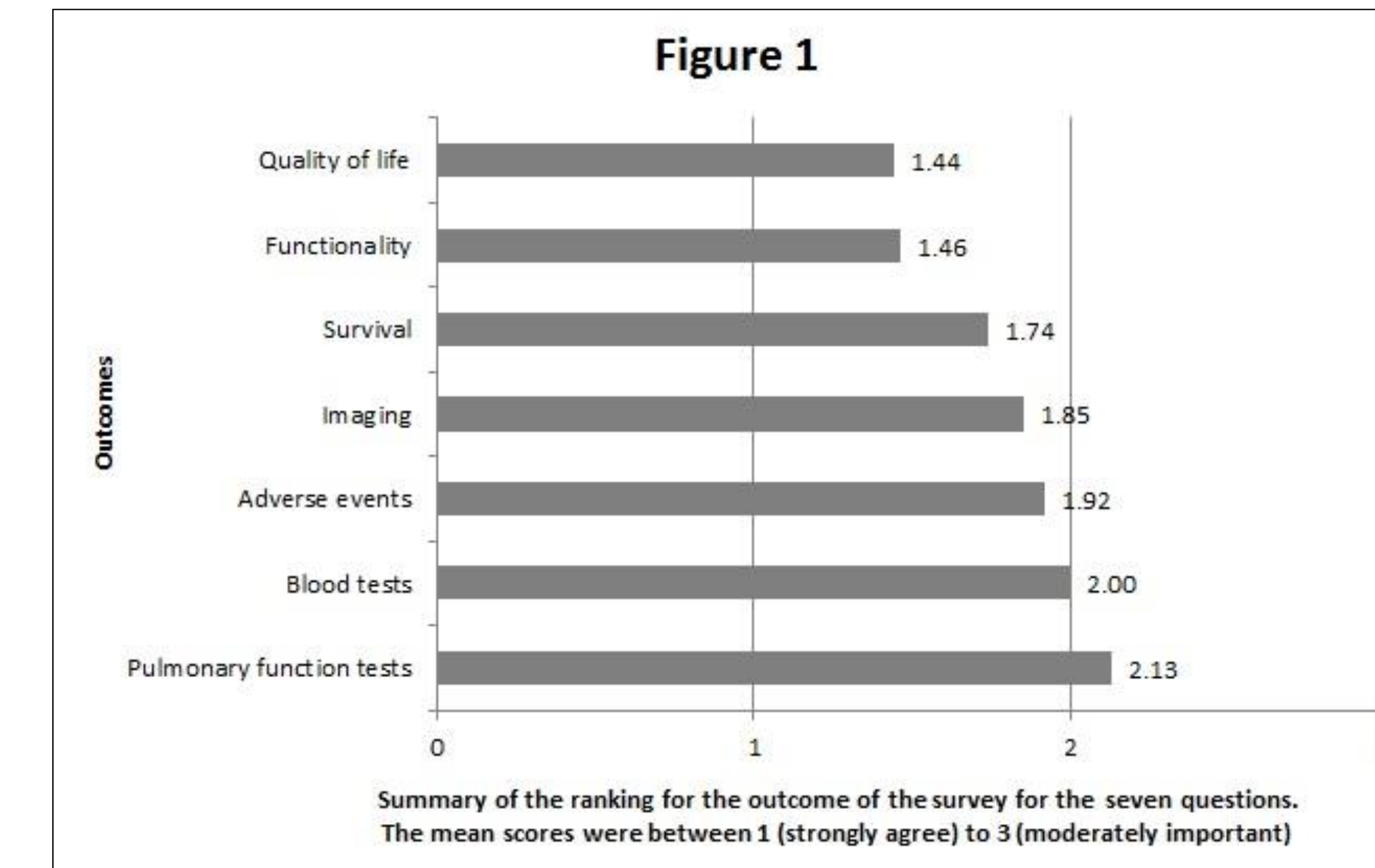
Methods

- The anonymous survey asked patients to rate the following outcomes using a 5-point rating scale
 - 1 extremely important, 2 very important, 3 moderately important, 4 slightly important, 5 not important at all
- The survey was available online in six languages (Dutch, German, English, Italian, Spanish, French) during January and February 2018.
- The data were analysed using a calculation of the average across all ratings.
- People diagnosed with sarcoidosis were invited to participate via promotion mainly through sarcoidosis patient organisation networks.
- A themed analysis of all the respondents' comments was also performed.

Questionnaire

Outcome and definition
Quality of life Definition: The level of well-being a person feels which might include a standard of health (physical and/or mental), comfort and life satisfaction or other factors important to that person
Functionality Definition: the level at which the body (or specific parts of the body) is able to work and function as normal Examples: breathe better, have more energy, see better, or ache less.
Pulmonary function tests Definition: non-invasive tests that show how well a person's lungs are working. Different tests can measure lung volume, capacity, rates of flow and gas exchange.
Blood tests Definition: taking a sample of blood to help with diagnosis (including ACE test)
Imaging Definition: X-rays and scans e.g. chest X-ray, CT scan, PET scan which take photographic or digital pictures of the body. They can be used to help diagnose a lung condition and to monitor how a condition progresses.
Adverse events Definition: an undesired or harmful effect from a drug or medical intervention such as surgery; also known as side effects.
Survival Definition: the length of time a person will continue to live

Results



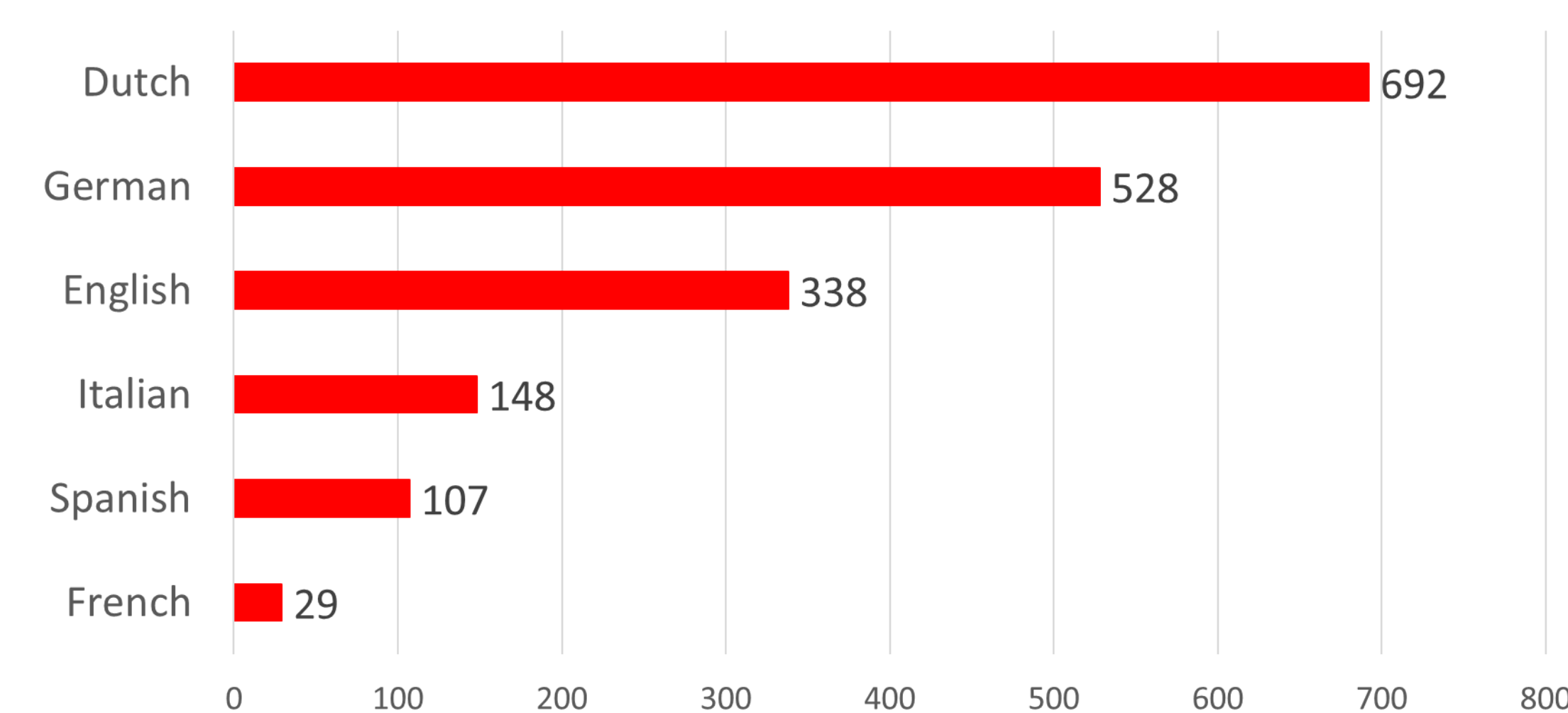
Themes noted in survey

- QoL and Functionality should be included in treatment outcomes**
The survey findings strongly show that respondents want QoL and Functionality to be included as outcomes in their treatment and care.
“Scans, tests and examinations are of course crucial in the treatment, but the well-being and the quality of life determine how much I suffer from sarcoidosis. And that is the most important thing.” (Survey respondent)
- Clinicians should work in a multidisciplinary way to ensure a holistic approach**
In sarcoidosis, it is important to identify every symptom and treat them as a whole rather than in isolation
“I think that although mental health is included in the definition of quality of life in this survey it is important enough to have its own category. Often sarcoidosis patients suffer from depression and low mood. Going through tests, chasing appointments, taking drugs everyday and seeing health deteriorate definitely takes its toll on mental health and it's important because it will ultimately underpin recovery and overall health and wellbeing.” (Survey respondent)
“A multidisciplinary approach with an emphasis on functionality is important. I have never had another doctor see me other than my internist.” (Survey respondent)
- Sarcoidosis specialists and specialist centres are needed in every country**
Sarcoidosis can be difficult to diagnose and treat when there is a lack of expertise, particularly for the rarer manifestations such as neurological sarcoidosis.
“It is important to increase the number of centres that deal with this disease as seen for other more widespread but also incurable diseases.” (Survey respondent)

Conclusions

- Quality of life and functionality were the highest priority for outcomes of sarcoidosis patients
- Blood tests and pulmonary function testing were not viewed as nearly important to the patient
- We encourage the sarcoidosis health and research community to partner with sarcoidosis patient organisations and to utilise this immense source of sarcoidosis lived experience to develop effective methods of measuring and incorporating QoL and Functionality outcomes as a way of improving sarcoidosis outcomes and future treatment.

Participants



A total of 1842 sarcoidosis patients completed the survey

Figure 1 shows the absolute results and Figure 2 the quantitative results, with the more important ratings shown on the left and the less important on the right. Quality of life and Functionality were the most important outcomes, while Blood tests and Pulmonary Function Tests (PFT) were least important. Imaging was ranked as a more important outcome than Blood tests or PFT.