

Building community-informed research funding priorities for a patient advocacy organization focused on sarcoidosis

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Introduction

The Foundation for Sarcoidosis Research (FSR) is the leading international organization dedicated to finding a cure for sarcoidosis and improving care for sarcoidosis patients through research, education, and support. Since its establishment in 2000, FSR has fostered over \$8 million in sarcoidosis-specific research efforts.

The FSR has served the community of those impacted by sarcoidosis and has supported dedicated sarcoidosis researchers and clinicians for 25 years.

Progress in the management of sarcoidosis is limited due to knowledge gaps relating to the biological processes leading to highly variable disease manifestations, the inability to predict disease course, and limited knowledge relating to risk factors for contracting the disease or for promoting disease severity.

To strategically prioritize research topics of most value to the diverse sarcoidosis community, FSR undertook a structured process to develop a new research agenda that will guide its funding priorities and strategic direction.

Methods

FSR employed a multi-stage mixed-method consensus-building approach, comprised of

1. Conducting a literature review
2. Convening a brainstorming workshop with key stakeholders (including physicians, patients, and caregivers)
3. Conducting individual stakeholder interviews
4. Facilitating a quantitative prioritization survey of the resulting list of priority research topics and values

The last stage employed the Best-Worst Scaling method requiring survey participants to make tradeoff decisions between research priorities. This method minimizes common biases experienced in traditional surveys and provided FSR with rankings and relative weights to facilitate group decision-making.

Conclusions

- This process revealed the sarcoidosis community's strong preference for identifying and standardizing outcome measures that matter to patients, followed by biomarker development and improved diagnostics.
- When implemented, this research agenda will represent a significant evolution in FSR's approach, establishing clear priorities while maintaining the flexibility to adapt to emerging opportunities.
- Through careful implementation and monitoring of key metrics and goals set for each of these priorities, FSR aims to accelerate progress toward improved treatments a cure for sarcoidosis.

Results:

Figure 1: FSR Research Prioritization Process Figure 2: Breakdown of Brainstorming Workshop Participation Figure 3: Interrelationships of Priorities

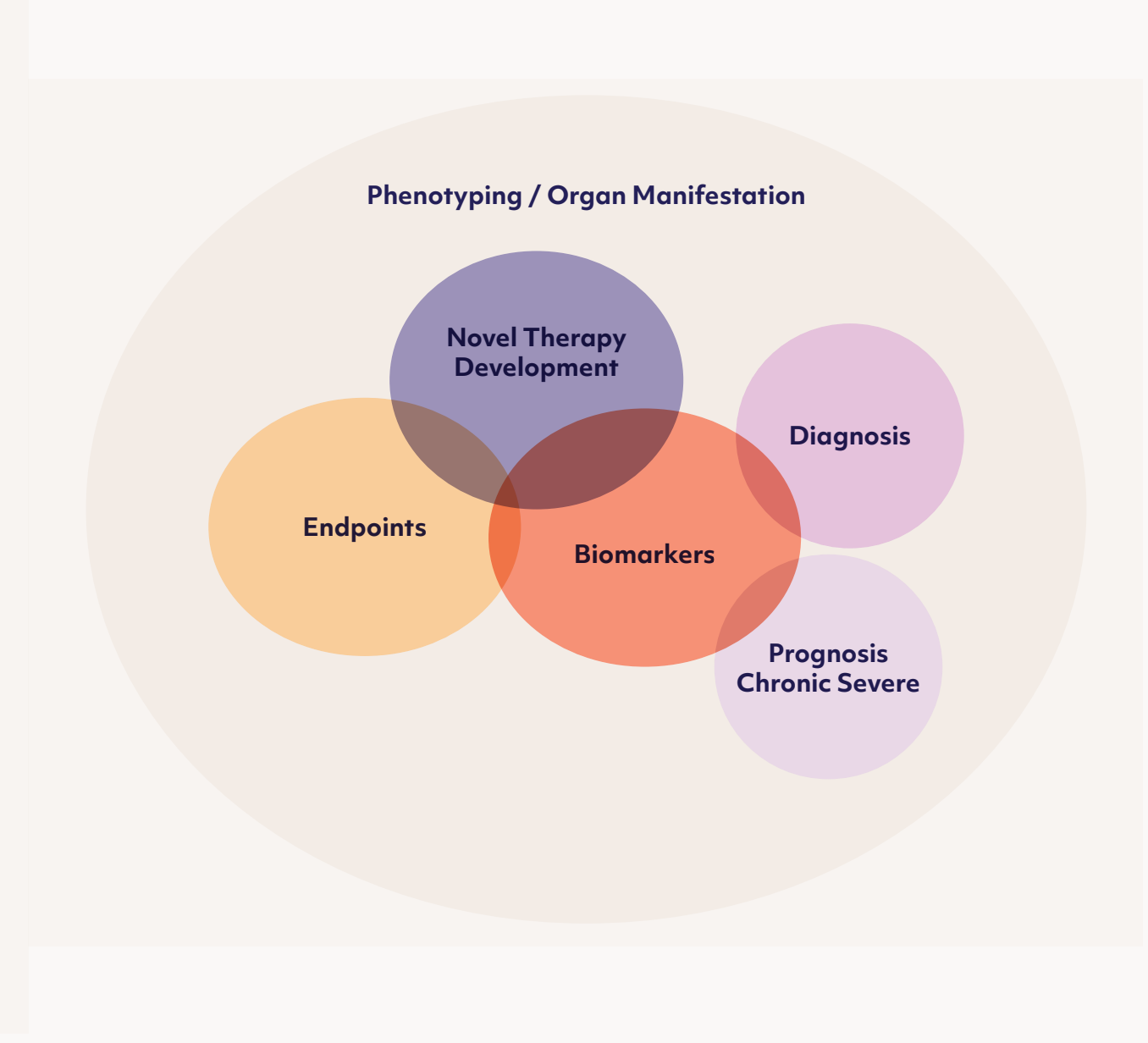
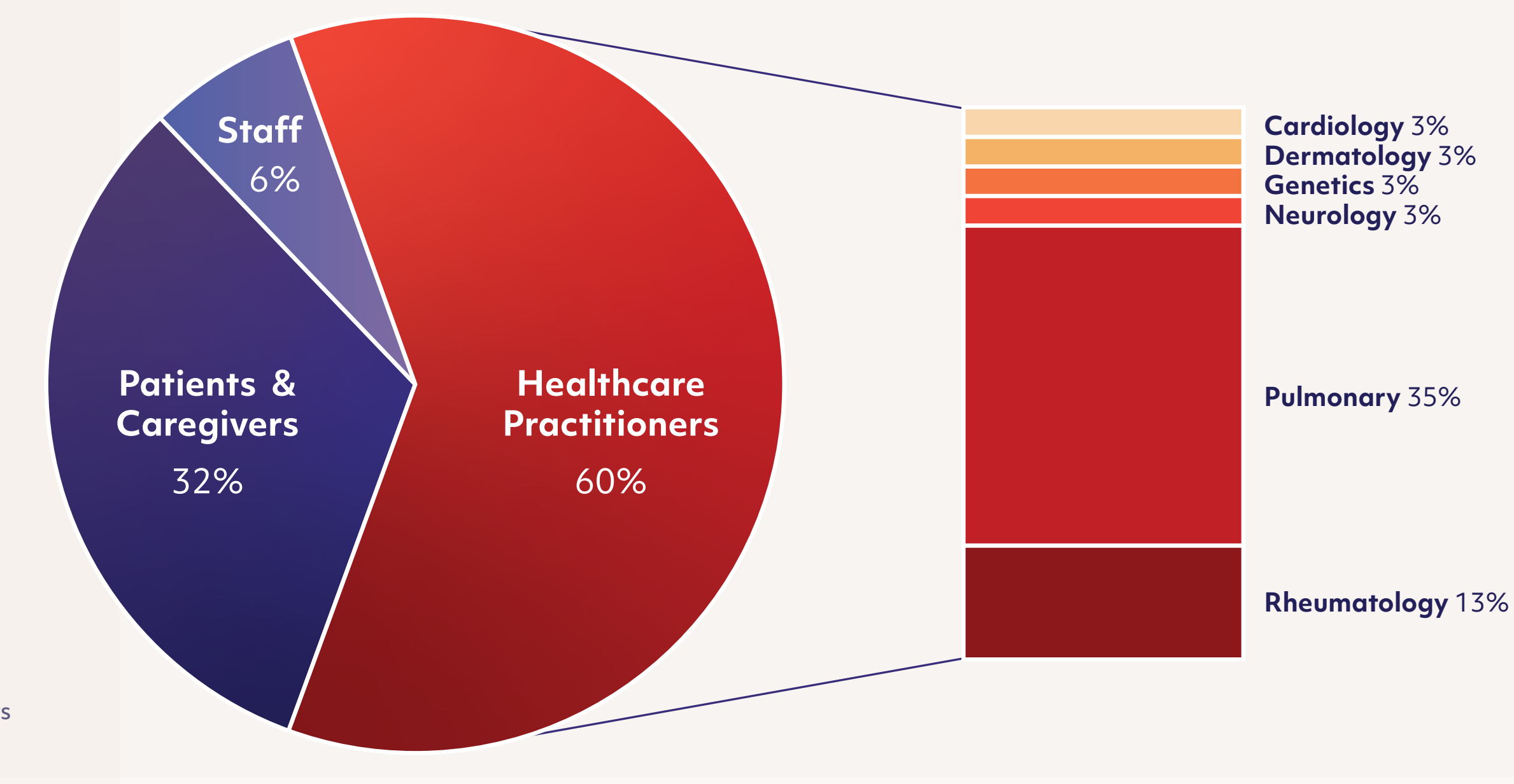
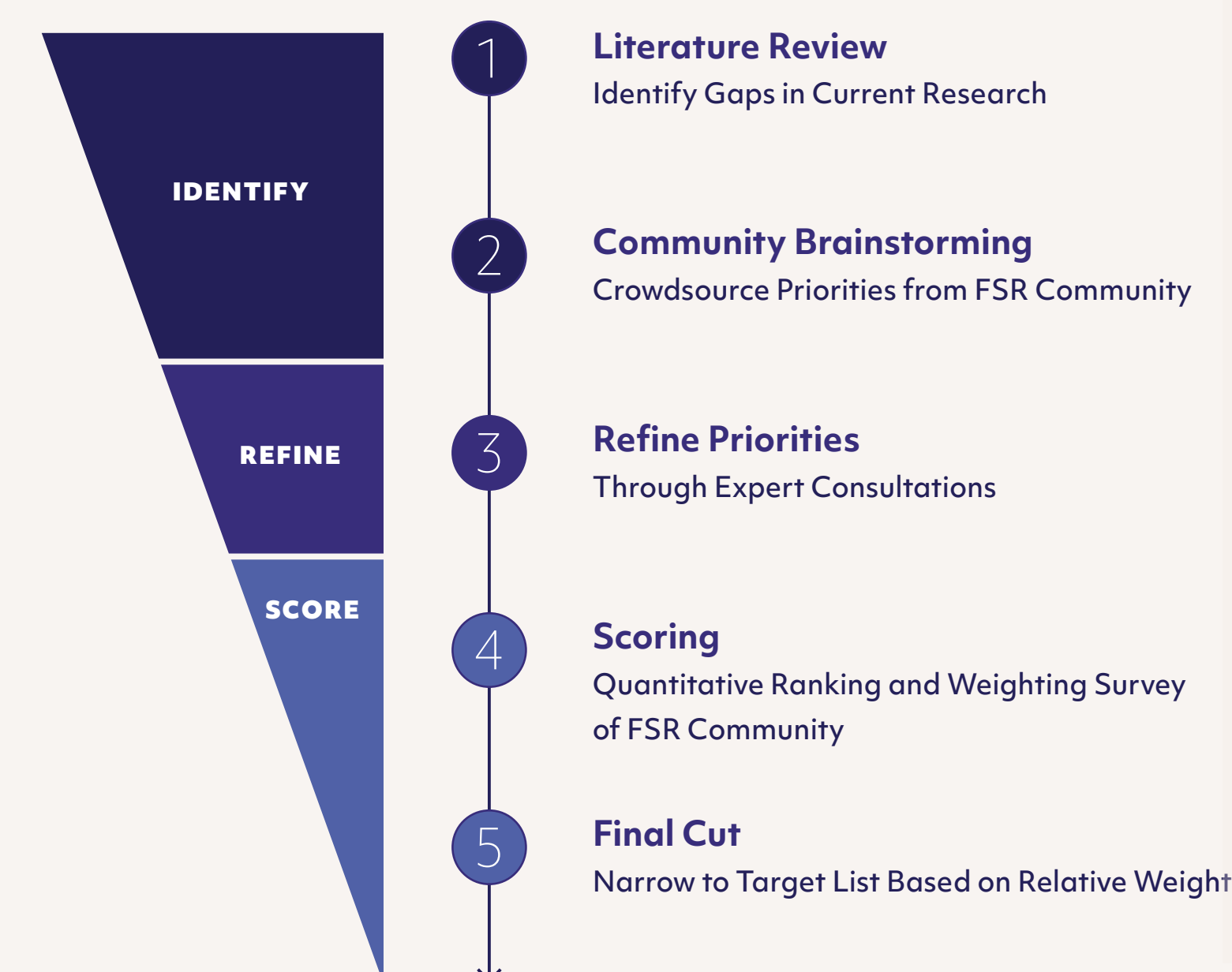
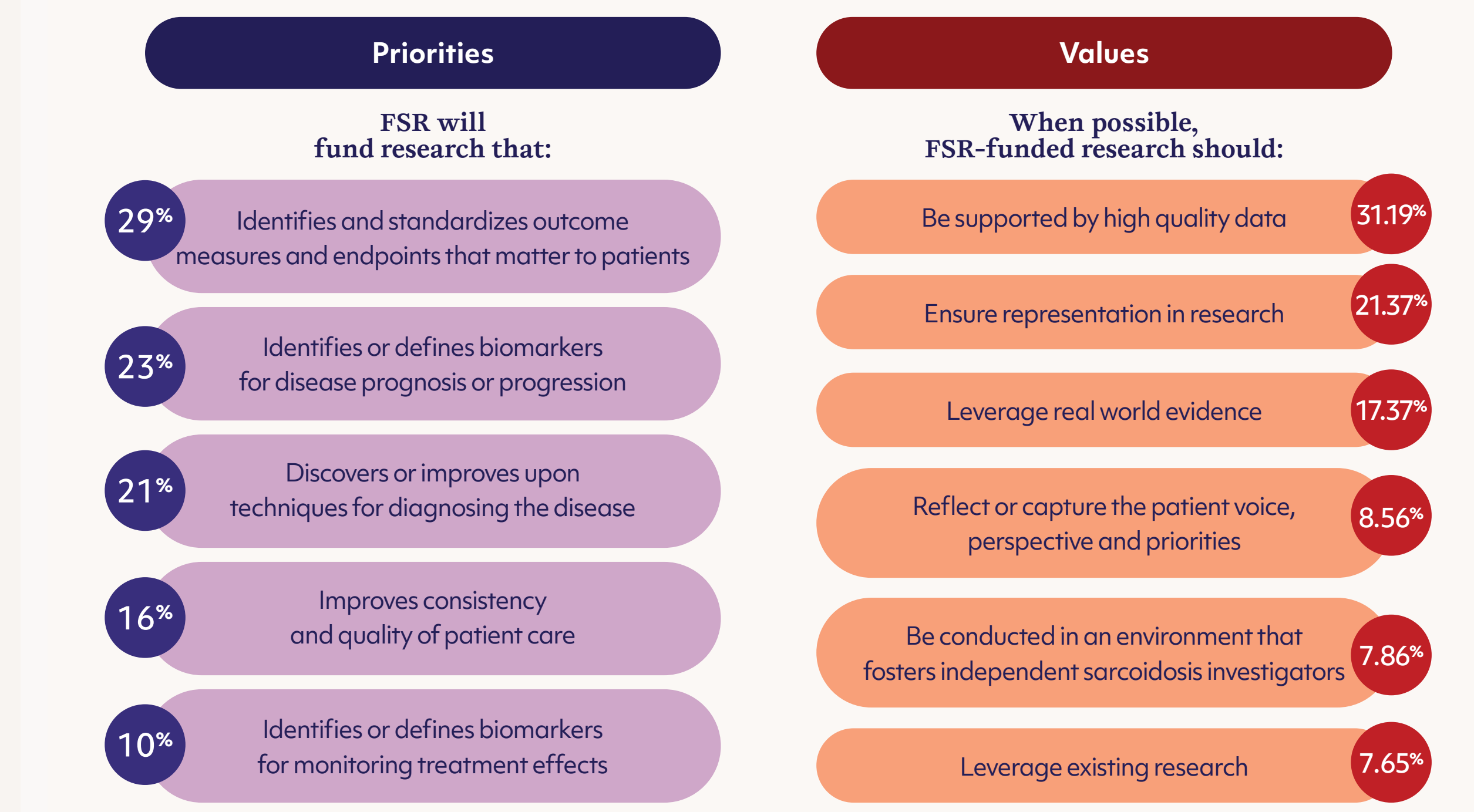


Figure 3: 24 Originally-Identified Criteria

- 1 Identifies or defines biomarkers
- 2 Addresses underserved, younger, vulnerable population
- 3 Helps to improve the patient experience
- 4 Supported by high quality data (RCT, sufficiently powered)
- 5 Supports standardization of outcome measures
- 6 Leverages real world evidence
- 7 Supports development of novel treatments
- 8 Support the management of disease (not treatments)
- 9 Addresses large(r) population of patients
- 10 Identifies or defines molecular phenotyping
- 11 Helps improve diagnosis
- 12 Ability to leverage other disease research
- 13 Identifies genetic basis of disease
- 14 Identifies or defines prevention or risk factors
- 15 Immediacy of impact/ applicability (vs delayed)
- 16 Identifies causes
- 17 Foundational (can help enable other areas of research)
- 18 Outcome measures and/or endpoints for clinical trials
- 19 Provide robust basic science data to serve as pilot data for "definitive" grant applications
- 20 Phenotyping and understanding severity
- 21 Understanding heterogeneity of disease
- 22 Important for the field
- 23 Important for the field and for FSR to support
- 24 Define natural history of disease and risk factors

Figure 5: FSR five primary Research Priorities and six Research Values to guide future FSR-funded research



The employed process was viewed as highly transparent and collaborative by participating sarcoidosis representatives and by community stakeholders (Figures 1 and 2). By working collaboratively with the FSR community to generate 24 "criteria" (Figure 3) and honing them down to eleven force-ranked priorities and values based on the existing interrelationships (Figure 4), FSR achieved its key objectives.

There exists an inherent conflict between demonstrating short-term progress and effectiveness for those impacted by sarcoidosis versus the more expensive and long-term process of working in the "harder" discovery of root biological causes and potential cures for future generations. FSR proposes to address this dilemma by investing additional advocacy resources to increase funding through federal grants or other sources to create the funding mechanisms to support and sustain this type of research.

The resulting Research Agenda (Figure 5) and weighting framework will be implemented into the research grant review process for FSR's 2025 funding mechanisms, providing additional insight alongside scientific merit criteria.

Acknowledgements and Resources:



Research Agenda



FSR Homepage
StopSarcoidosis.org

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