

Objectives

- MIHRA Foundation seeks to establish a credible, quantifiable and justifiable mechanism for people living with myositis diseases to impact the course of research.
- MIHRA Foundation's Patient Advisory Board and Board of Directors set out to understand & identify patient priorities in research and resource allocation across myositis diseases.
- To integrate patient voice in research planning and funding allocation for the MIHRA Foundation & other research funding bodies.

Background

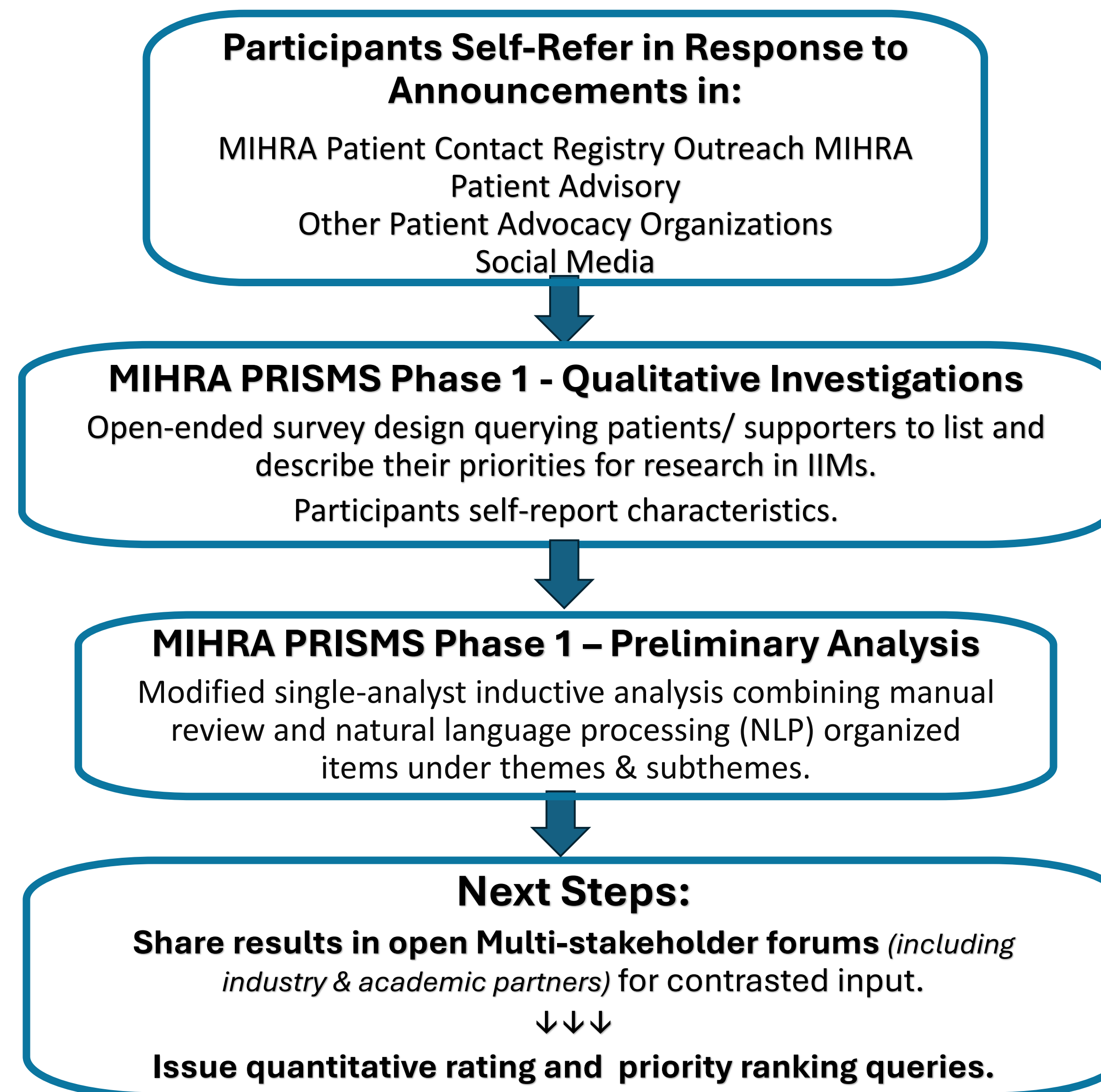
- Idiopathic inflammatory myopathies (IIMs) or myositis diseases are rare, heterogeneous autoimmune disorders that can involve muscle, lung, skin, heart, and gastrointestinal manifestations.
- During patient conferences & seminars, people living with IIMs voice concerns of diagnostic delay, endpoints that are exclusionary in trials or poorly reflective of patient experience.
- MIHRA Foundation is a non-profit research organization committed to patient-relevant, -centered & -driven efforts.
- The **MIHRA Foundation Patient Advisory** & MIHRA Board of Directors, comprised of scientific & patient leaders serving the international patient community, established MIHRA PRISMS, a patient-initiated study to inform IIM research agendas and funding for MIHRA and external grantors.
- We report the preliminary results of the 1st phase of PRISM.

Methods

- MIHRA PRISMS (NCT07374107) is a global multi-phase, mixed methods study (single-site IRB #1404410). using online approaches (open-ended narratives, community forums/focus groups, and rating/ranking surveys) with wide-net sampling to attain representation across IIMs and characteristics.

Methods cont'd

Fig. 1 Methods Steps



Results

217 respondents contributed 784 entries with the following spread over high level concepts. Entries per respondent: 3 (median), 2-5 (IQR), 1-17 (range). Available data for time to diagnosis n=194 (89.4%).

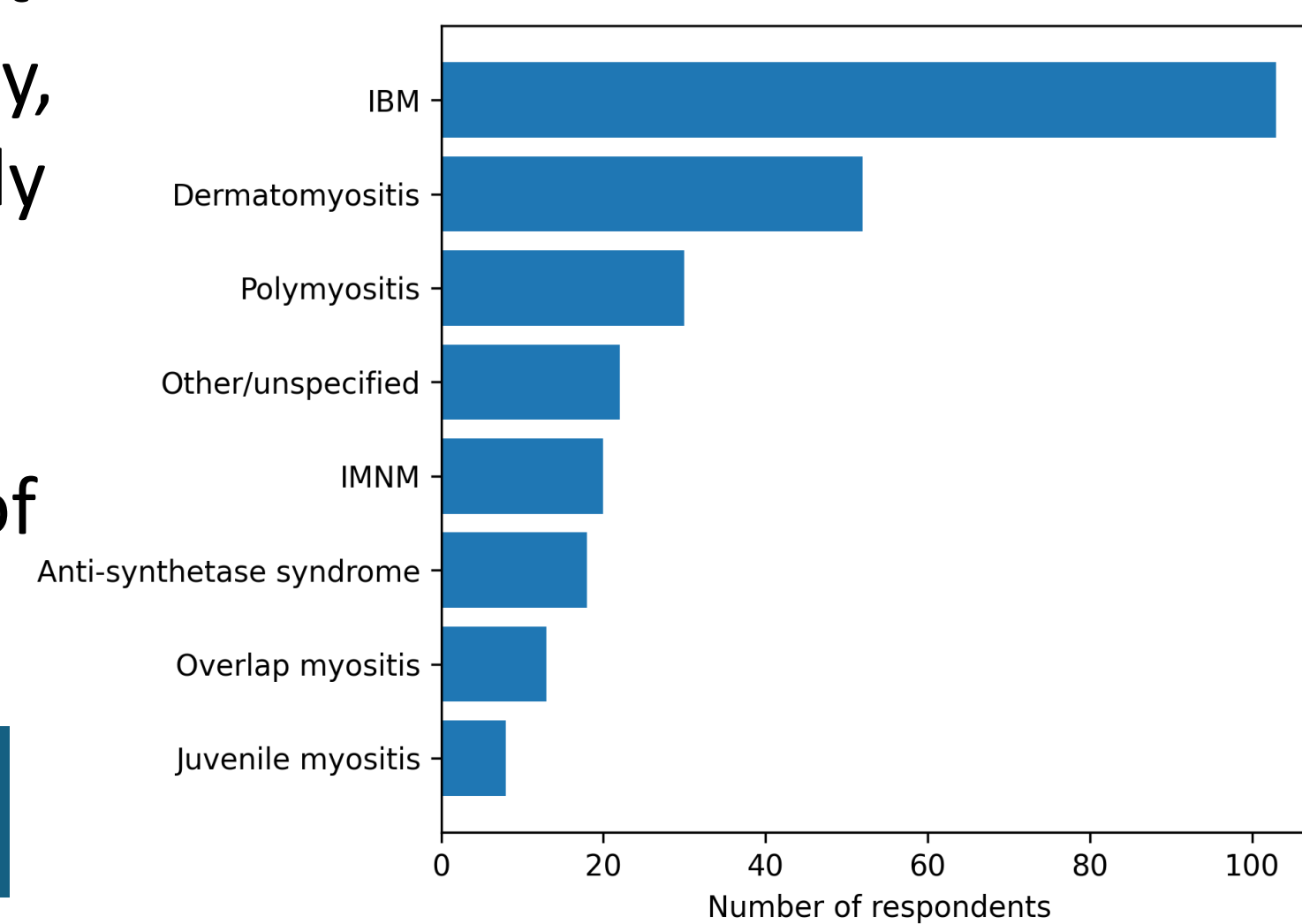


Fig. 2 (above) depicts participant distribution of disease type

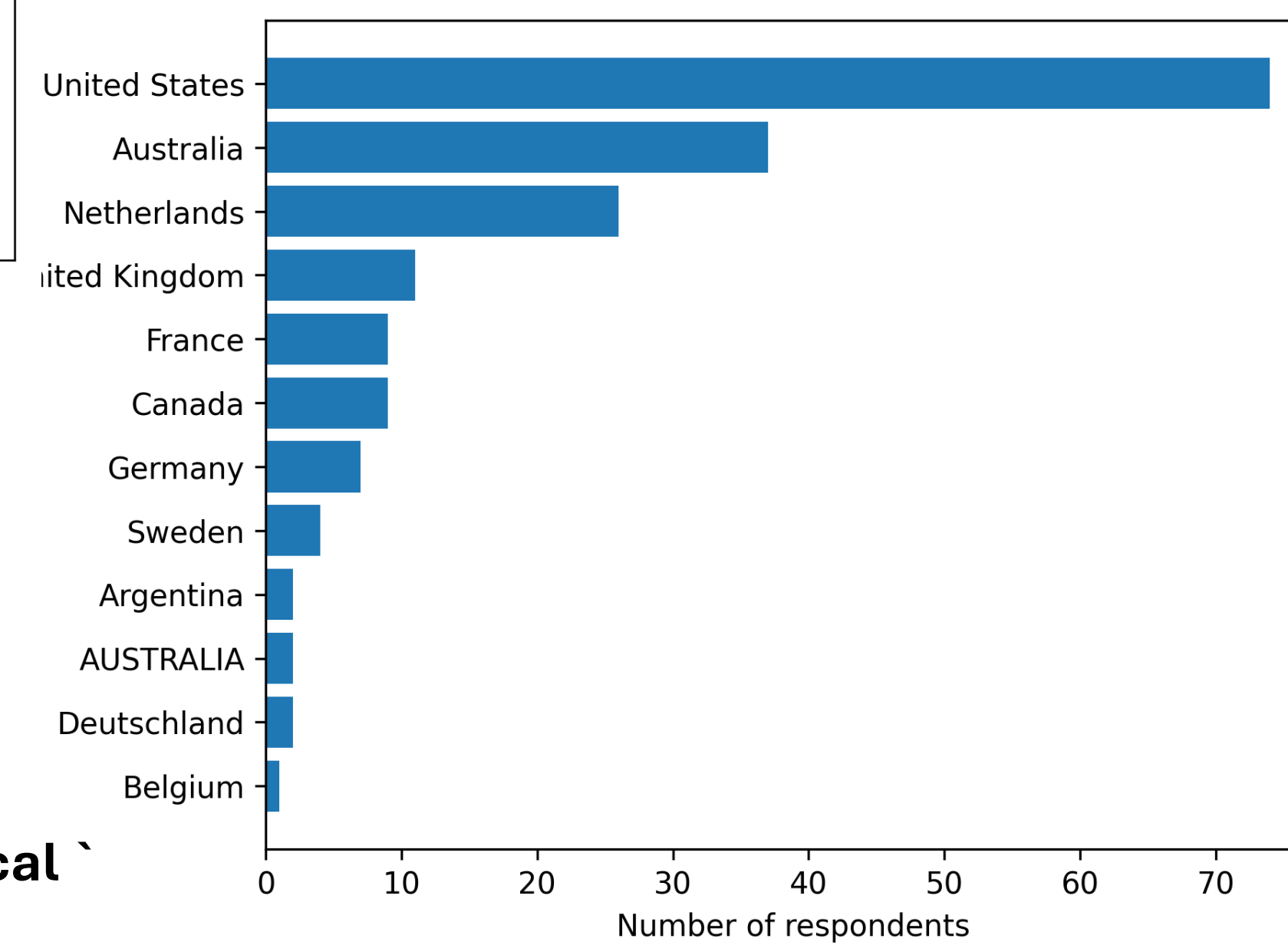


Fig. 3 (right) depicts geographical spread of participants

Results cont'd

Select results are summarized below as: 1. **percent of respondents (%R)** mentioning each code and 2. **percent of total priority entries (%E)**

- Treatment/cure (59.4%R; 24.6%E)
- Cause/mechanisms (39.6%R; 18.0%E)
- Diagnosis/recognition (32.3%R; 11.9%E)
- Quality of life (QoL) &/or Symptom burden (25.8% R; 10.1% E) [QoL (18.0%R; 6.1%E), Symptom (13.8% R; 4.7% E)]
- Monitoring/progression/outcomes (23.0%R; 8.5%E)
- Rehab/exercise (19.8%R, 7.4%E)
- Organ complications (18.0%R)
- Nutrition (15.2%R)
- Care delivery/access/resources by 12.9%R
- Mental health (11.5%R)
- Triggers/flares (11.1%R)
- Dysphagia (9.7%R)
- Professional education/awareness (5.5%R)

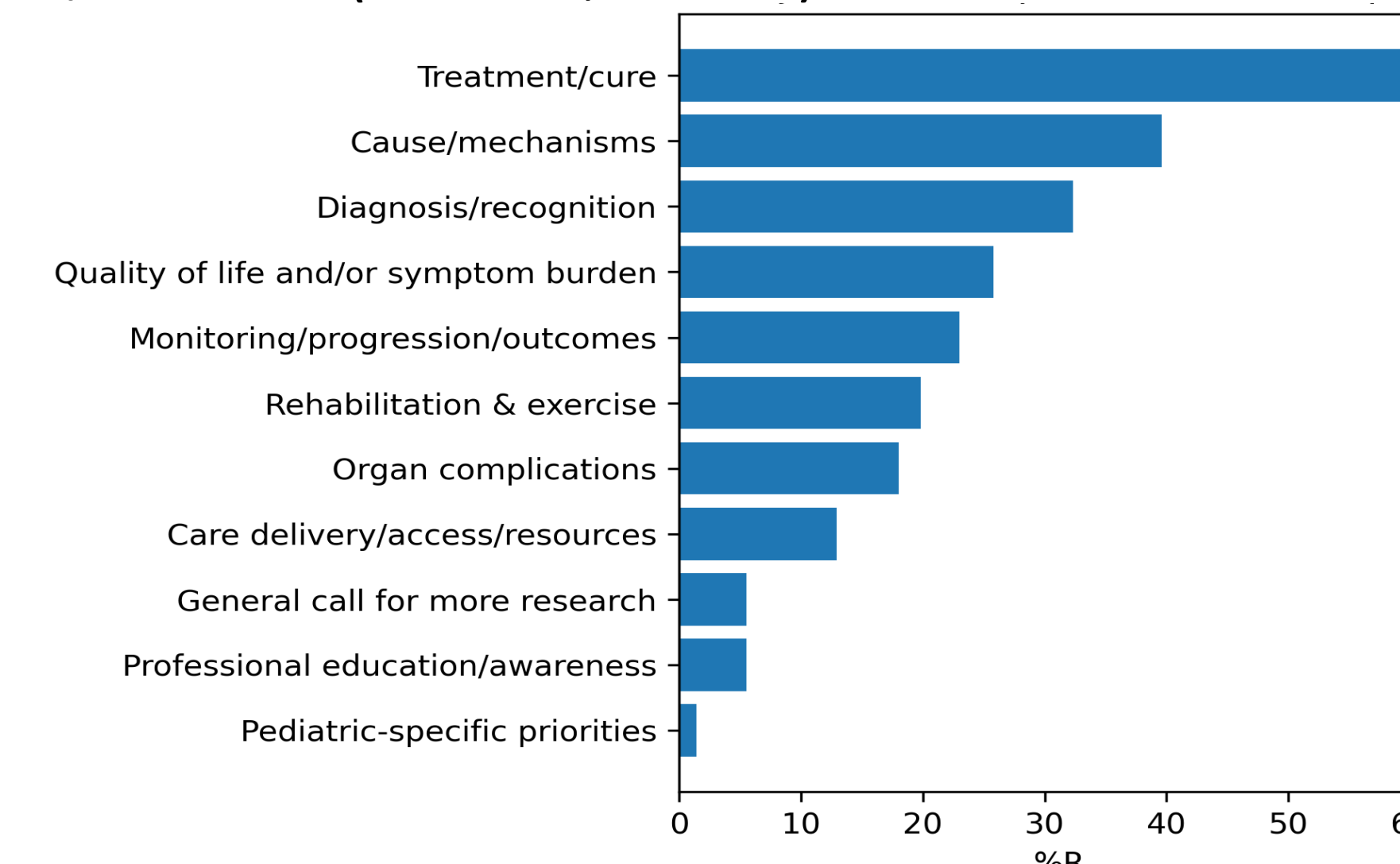


Fig. 4 % of respondents with >=1 priority per theme

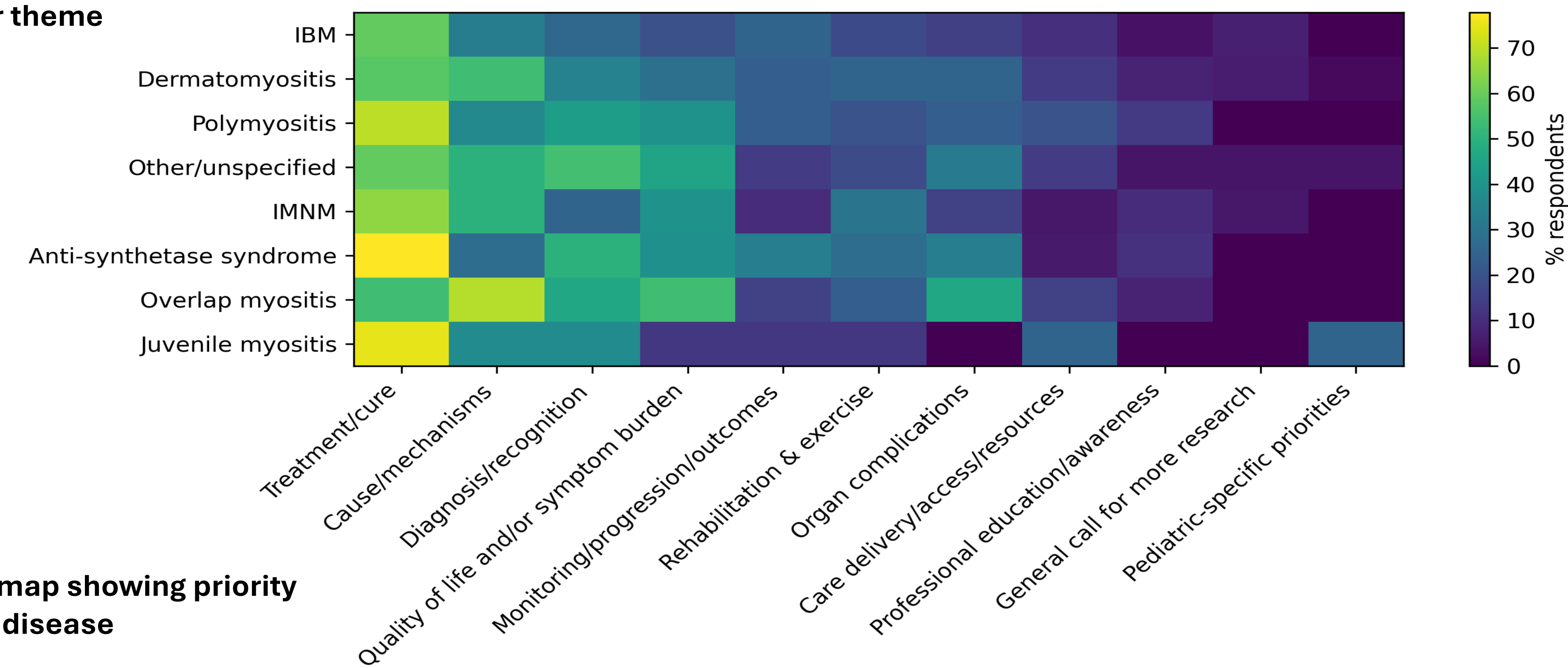


Fig. 5 Heatmap showing priority themes by disease

Conclusion

- PRISMS is poised to capture and quantify patient-voiced research priorities across IIMs to foster patient-relevant research.
- PRISMS elucidated patterns of patient-perceived scientific advancement which uphold current funding (favors therapeutics and biomarkers) with substantial expansion to poorly funded areas: rehabilitation, nutrition, mental health, symptom burden and QoL.
- PRISMS results will be published for use by funders and research groups external to MIHRA to support patient-centered research selection.
- PRISMS is intended to repeat every 2-3 years allowing priority mapping to keep pace with evolving treatments, diagnostics, lived experience and as patient needs evolve.