



Role Title: Research Fellow - Spinal Muscular Atrophy

Term: Fixed-term contractor position for 12-15 months

Location: ICHOM's Headquarters are in the USA with teams also in the UK and Europe. This role can be a fully remote working role but the team of direct reports are on GMT/CET/EST time zones and the candidate will need to be in a similar time zone to ensure the team has support during their working hours.

Background

ICHOM (www.ichom.org) is a non-profit organisation committed to promoting value-based healthcare globally through universal measurement and reporting of patient outcomes

There is a value crisis in healthcare globally – spending grows unsustainably, while clinical practice and outcomes continue to vary significantly and clinical staff are increasingly distressed and many leave their professions. Solving the crisis requires us to reorient the global health systems to focus more on the health achieved for patients and the population at large. These value-based principles build on a definition of “outcomes matter to patients” and the basing of performance assessment and payments on these outcomes. The International Consortium for Health Outcomes Measurement (ICHOM) is a non-profit organisation established in 2012 by the founders and early pioneers of value-based healthcare to address this crisis. At ICHOM, our contribution to our first decade has primarily been to empower patient and clinical leaders to identify and standardize the most important clinical, quality of life, and function results for health care. Having entered our second decade, we are increasingly seeking to enable transparent large-scale use by various stakeholders to achieve patient-centric health system transformation. Using a modified Delphi consensus process and together with international multidisciplinary panels of experts, ICHOM develops the evidence-based patient co-created standardized sets of patient-centred outcomes measures (sets). To date, ICHOM has developed 47 sets for conditions that account for nearly 60% of the global disease burden. The sets are available in IT-ready interoperable formats (including JSON, FHIR) and have been implemented in over 500 care settings in over 42 countries, contributing to better patient engagement with shared decision making, benchmarking and quality improvement, reduced care costs, RCT evaluation of novel treatment pathways all based on patient-important outcomes. In addition, ICHOM supports the use of sets through webinars, accreditation of providers delivering value to patients, enabling federated analysis and learning collaboratives, and hosting the largest value based care meeting- our annual conference.

We are seeking a **Research Fellow** who would like to join us in this effort to develop a Set of Patient-Centered Outcome Measures for Spinal Muscular Atrophy.

Duties and Responsibilities

The Research Fellow works alongside an ICHOM Project Manager and the Working Group chair(s), being primarily responsible for the content creation for the Working Group meetings. This includes the following:

- Defining the scope of the work
- Reviewing the outcomes research literature and existing registry efforts

- o Includes analysis of common in-use clinical outcomes, their epidemiology, and the common validated patient-reported outcomes and their methodological properties
- Drafting the set of proposed standard measures and their definitions
- Conducting similar work (literature review, questionnaire input, drafts of proposals) for case-mix factors and their definitions
- Providing input into the Working Group presentations
- Authoring publication in a peer reviewed-journal announcing the standard measure set
- Other content-focused tasks, as appropriate

Qualifications and skills

- Experienced in conducting literature reviews
- Experience with the evaluation of Patient Reported Outcome Measures (PROMS). Clinical knowledge, i.e. urology, nephrology, is preferred but not required.
- Subject expertise in spinal muscular atrophy is desirable but not required.

Time Commitment

The commitment is estimated to average 10-12 hours a week for about 15 months to arrive at the final Set of Patient-Centered Outcome Measures. Beyond this commitment, we welcome the Research Fellow to stay involved as the group moves into real world applications, with the possibility of subsequent academic publications.

Location

The Research Fellow is not expected to work at the ICHOM offices. Applicants from outside the United States and United Kingdom are welcome. However, the Research Fellow is asked to participate in weekly teleconferences with the ICHOM project team. The Research Fellow is also expected to join monthly calls with the working group which typically last 90-120 minutes.

Compensation

We believe the greatest benefit from participating as a Research Fellow is the academic experience and network development, but we also recognise the opportunity cost of participation. For this, we offer a bundled research stipend of USD [\$10,000.]

Application Procedure

Interested candidates should send a CV/Resume and a short cover letter to both jobs@ichom.org and the Project Manager, Yasmine Saoud at y.saoud@ichom.org. Applications will be reviewed on a rolling basis with a view to appoint a candidate by July 2025.