

Table S1: Statements shown in priority order with rating score shown

Priority ranking	Statement	High priority % score
1	Improving methods of identifying patients with active disease	81%
2	Availability of drugs for LAM in all EU countries	81%
3	All patients can access a specialist LAM centre	81%
4	Lung transplants should be available to more patients, and with shorter waiting times	79%
5	Improving non-invasive diagnosis	78%
6	Patients can access treatments such as low dose sirolimus/everolimus	77%
7	Improving care for patients in non-specialist hospitals/services	77%
8	Opportunity for patients to hear about and participate in clinical trials	75%
9	Improving diagnostic biomarkers so that diagnosis is faster and more definitive	75%
10	Development of a European-wide organ donor registry	73%
11	Combination therapies available to patients	72%
12	Collaboration between research institutions such as the ERS and LAM patient organisations	71%
13	Importance of the European LAM Federation and national LAM patient organisations in giving support to patients	70%
14	Increasing the number of small scale clinical trials and improving the methodology	68%
15	Developing a European database of specialist LAM centres	67%
16	Making travel with oxygen easier for patients	67%
17	Opportunity for patients to donate tissue and blood to research centres	65%
18	Importance of psychological support	63%
19	Patients able to benefit from new developments in TSC	62%
20	Improving ways to model LAM so that more research can be conducted without the participation of patients	61%
21	Use of vascular endothelial growth factor-D (VEGFD) to decide treatment or adapt therapy	61%
22	Measuring the impact of LAM on quality of life	60%
23	Guidance on physiotherapy	59%
24	Creation of an EU level registry of people with LAM	59%
25	Giving clear guidance on lung biopsy and its usefulness in diagnosis	53%
26	Guidance on nutrition	49%