

## Supplementary data

Table S1. Summary of the key sources by relevant variable and evidence quality

COUNTRY	PE RATE	% SURVIVE PE	% CTEPH in PE	% Unknown-PE CTEPH	CTEPH DIAGNOSIS RATES	FUNCTIONAL STATUS AT DIAGNOSIS	OPERABILITY ASSESSMENT	OPERABILITY RATE	OPERATED RATE	% SURVIVE SURGERY	PERSISTENT/RECURRENT DISEASE RATE
USA	1	1	8, 11, 12, 13, 14, 15, 16, 21	18	Benchmarked to PEAs	9, 17, 19	24	17, 18, 20, 22	17, 18, 20, 22	23	9, 10, 18, 21, 22
Japan	6, 7, 25	Based on US	Back-calculated to be 10.2%	25	Assumed 20%	9, 17, 19	24	17, 18, 20, 22	17, 18, 20, 22	23	9, 10, 18, 21, 22
France	2	Based on US	8, 11, 12, 13, 14, 15, 16, 21	18	Benchmarked to PEAs	9, 17, 19	24	17, 18, 20, 22	17, 18, 20, 22	23	9, 10, 18, 21, 22
Germany	3	Based on US	8, 11, 12, 13, 14, 15, 16, 21	18	Benchmarked to PEAs	9, 17, 19	24	17, 18, 20, 22	17, 18, 20, 22	23	9, 10, 18, 21, 22
Italy	Based on Europe (four countries)	Based on US	8, 11, 12, 13, 14, 15, 16, 21	18	Benchmarked to PEAs	9, 17, 19	24	17, 18, 20, 22	17, 18, 20, 22	23	9, 10, 18, 21, 22
Spain	5	Based on US	8, 11, 12, 13, 14, 15, 16, 21	18	Benchmarked to PEAs	9, 17, 19	24	17, 18, 20, 22	17, 18, 20, 22	23	9, 10, 18, 21, 22
UK	4	Based on US	8, 11, 12, 13, 14, 15, 16, 21	18	Benchmarked to PEAs	9, 17, 19	24	17, 18, 20, 22	17, 18, 20, 22	23	9, 10, 18, 21, 22

CTEPH, chronic thromboembolic pulmonary hypertension; PE, pulmonary embolism; PEA, pulmonary endarterectomy.

- Generally large-sized samples, new(er) data, unbiased patient samples, with little to no additional calculation needed
- Medium- or small-sized patient samples, older data, with moderate use of additional calculations (such as applying other country data) involved in the final assumption, or some degree of bias in the patient samples
- Small-sized patient samples, older data, significant bias in patient samples, with additional calculations (such as applying other country data) being largely responsible for assumptions

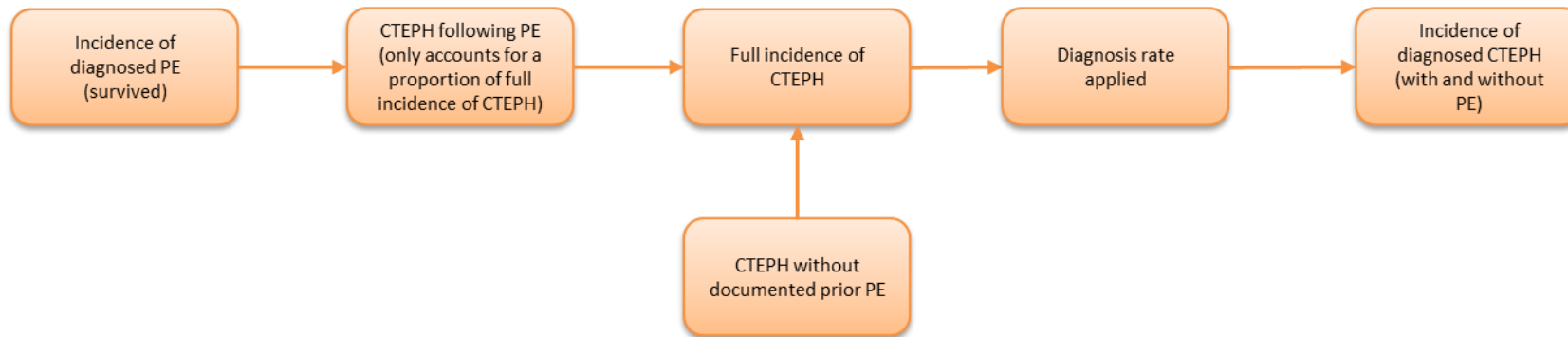
1	The Healthcare Cost and Utilization Project Nationwide Inpatient Sample, 2010 (US-based)
2	French national database, French Institute for Public Health Surveillance (PMSI), 2011
3	Incidence rate of pulmonary embolism in Germany: data from the federal statistical office; <i>J Thromb Thrombolysis</i> 2010 Apr; 29(3): 349–53
4	The UK Hospital Episode Statistics, 2010
5	The Spanish National Institute of Statistics INEbase Hospital Morbidity Survey, 2009–2010
6	Sakuma M. Venous thromboembolism: deep vein thrombosis with pulmonary embolism, deep vein thrombosis alone, and pulmonary embolism alone. <i>Circ J</i> 2009 Feb; 73(2): 305–9
7	The Japanese Intractable Disease Survey (CTEPH), 2010
8	Otero R. Echocardiographic assessment of pulmonary arterial pressure in the follow-up of patients with pulmonary embolism. <i>Thromb Res</i> 2011 Apr; 127(4): 303–8
9	Freed DH. Survival after pulmonary thromboendarterectomy: effect of residual pulmonary hypertension. <i>J Thorac Cardiovasc Surg</i> 2011 Feb; 141(2): 383–7
10	Rahnavardi M. Pulmonary thromboendarterectomy for chronic thromboembolic pulmonary hypertension: a systematic review. <i>Ann Thorac Cardiovasc Surg</i> 2011; 17(5): 435–45
11	Martí D. [Incidence of symptomatic and asymptomatic chronic thromboembolic pulmonary hypertension]. <i>Arch Bronconeumol</i> 2010 Dec; 46(12): 628–33
12	Poli D. Incidence of recurrent venous thromboembolism and of chronic thromboembolic pulmonary hypertension in patients after a first episode of pulmonary embolism. <i>J Thromb Thrombolysis</i> 2010 Oct; 30(3): 294–9
13	Klok FA. Prospective cardiopulmonary screening program to detect chronic thromboembolic pulmonary hypertension in patients after acute pulmonary embolism. <i>Haematologica</i> 2010 Jun; 95(6): 970–5
14	Surie S. Active search for chronic thromboembolic pulmonary hypertension does not appear indicated after acute pulmonary embolism. <i>Thromb Res</i> 2010 May; 125(5): e202–5
15	Noble S. Epidemiology and pathophysiology of cancer-associated thrombosis. <i>Br J Cancer</i> 2010 Apr 13; 102(Suppl. 1): S2–9
16	Dentali F. Incidence of chronic pulmonary hypertension in patients with previous pulmonary embolism. <i>Thromb Res</i> 2009 Jul; 124(3): 256–8
17	Bonderman D. Risk factors for chronic thromboembolic pulmonary hypertension. <i>Eur Respir J</i> 2009 Feb; 33(2): 325–31
18	Pepke-Zaba J. Chronic thromboembolic pulmonary hypertension (CTEPH): results from an international prospective registry. <i>Circulation</i> 2011 Nov 1; 124(18): 1973–81

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19	Mayer E. Surgical management and outcome of patients with chronic thromboembolic pulmonary hypertension: results from an international prospective registry. <i>J Thorac Cardiovasc Surg</i> 2011 Mar; 141(3): 702–10
20	Hurdman J. ASPIRE registry: assessing the Spectrum of Pulmonary hypertension Identified at a REferral centre. <i>Eur Respir J</i> 2012 Apr; 39(4): 945–55
21	Korkmaz A. Long-term outcomes in acute pulmonary thromboembolism: the incidence of chronic thromboembolic pulmonary hypertension and associated risk factors. <i>Clin Appl Thromb Hemost</i> 2012 Jun; 18(3): 281–8
22	Jansa P. Centre for Pulmonary Hypertension, Department of Cardiology and Angiology Charles University, Prague, Czech Republic, 7th Bayer International PH Symposium 2012; March 3–4; Rome, Italy
23	Condliffe R, Kiely DG, Gibbs JSR. Prognostic and aetiological factors in chronic thromboembolic pulmonary hypertension. <i>Eur Respir J</i> 2009; 33: 332–37
24	Gall H, Preston IR, Hinzmann B, Heinz S, Jenkins D, Kim NH, Lang IM. An international physician survey of chronic thromboembolic pulmonary hypertension management. <i>Pulm Circ</i> 2016; 6: 472–482
25	Tanabe N. Analysis of chronic thromboembolic pulmonary hypertension (CTEPH) based on data from clinical research form; CTEPH report by MHWL's Specified, Rare and Intractable Disease Workshop; citation not translated; published 2008

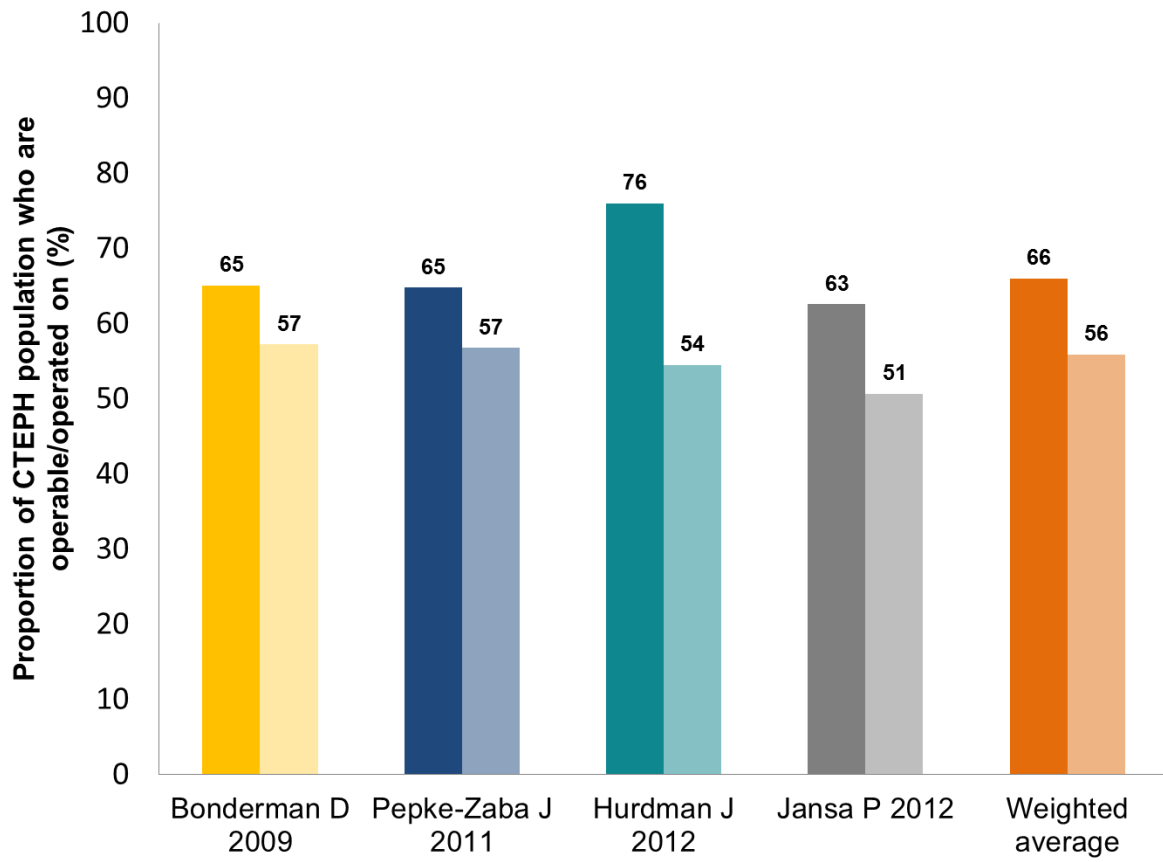
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**Figure S1.** Components of the epidemiological incidence projection methodology



CTEPH, chronic thromboembolic pulmonary hypertension; PE, pulmonary embolism.

**Figure S2.** Proportions of patients with CTEPH referred and assessed for operability judged to be operable (darker bars) and the proportions of patients with CTEPH undergoing PEA (lighter bars)



CTEPH, chronic thromboembolic pulmonary hypertension; PEA, pulmonary endarterectomy.