

TABLE 1 Outcome of cases with chronic thromboembolic pulmonary hypertension diagnosed by the Scottish Pulmonary Vascular Unit between 2000 and 2008

	Aug 2000 – July 2004	Aug 2004 – July 2008	Annual rate per million for 2004–2008
Cases diagnosed	18	50	2.5
Cases referred to Papworth	16	44	2.2
Cases not referred	2	6	
Patients referred to Papworth			
Operable	8	26	1.3
Not operable	7	13	
Awaiting decision	0	4	
Died before being seen	1	1	
Outcome if operable			
PEAs	6	20	1.0
Died pre-operatively	2	0	
Operable but declined	0	5	
Awaiting operation	0	1	

Data are presented as n. PEA: pulmonary endarterectomy. These data show a number of possible additional reasons for the low Scottish rate seen in the study by Toshner *et al.* [1].

increase in referral rate to the SPVU of all forms of pulmonary hypertension, which doubled between 2003 and 2007. We do not know if the data for the English units show a similar activity trend. For the period 2004–2008, the annual Scottish PEA rate was 1.0 cases·million⁻¹·yr⁻¹. This is much closer to the average East of England rate for 2000–2006 (1.27 cases·million⁻¹·yr⁻¹) than the figure calculated by TOSHNER *et al.* [1] for Scotland for 2000–2006 (0.57 cases·million⁻¹·yr⁻¹).

Secondly, the incidence of operable patients in Scotland between 2004 to 2008 was 1.3 cases·million⁻¹·yr⁻¹ (*cf.* the PEA rate for East of England patients 1.27 cases·million⁻¹·yr⁻¹). However, five (19%) of the Scottish CTEPH patients who were deemed operable declined surgery. This compares with 9% of patients who declined surgery in the UK as a whole [2]. In four out of five of these cases, the patients had mild disease and did not consider the risk-benefit ratio of surgery to be in their interest. The fifth patient did have more severe disease but was aged 81 yrs and both distance and risks of surgery were deterrent factors. We do not know the proportion of operable patients who proceed to surgery for the other UK regions. It may be that this is lower in Scottish patients because of the greater distances involved or different interpretation of the risks of surgery.

Thirdly, it is the policy of our unit to refer all patients diagnosed with CTEPH to Papworth Hospital (Cambridge, UK) for their opinion on operability. Despite that policy, this opinion was not obtained in eight (12%) of our cases. We have reviewed these cases locally since the publication of the study by Toshner *et al.* [1] and are confident that these do not represent any missed operable cases.

In conclusion, current data from the Scottish Pulmonary Vascular Unit are closer to that seen in UK areas with nationally designated centres than estimated in the study by TOSHNER *et al.* [1] and add support to the conclusion that all

such centres promote increased referral rates for pulmonary endarterectomy. Analysis of incidence of technically operable cases rather than pulmonary endarterectomys performed might give a more accurate comparison between regions.

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STATEMENT OF INTEREST

A statement of interest for A.J. Peacock can be found at www.erj.ersjournals.com/misc/statements.shtml

REFERENCES

- 1 Toshner M, Suntharalingam J, Goldsmith K, *et al.* Current differences in referral patterns for pulmonary endarterectomy in the UK. *Eur Respir J* 2008; 32: 660–663.
- 2 Condliffe R, Kiely DG, Gibbs JSR, *et al.* Improved outcomes in medically and surgically treated chronic thromboembolic pulmonary hypertension. *Am J Respir Crit Care Med* 2008; 177: 1122–1127.

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From the authors:

We thank M.K. Johnston and co-workers for their further work on national referral rates of patients with chronic thromboembolic pulmonary hypertension (CTEPH) in the UK. In our original paper [1], we offered the relative lack of specialist centres over a large geographical area as an explanation for the lower referral rates in Scotland. We find their further analysis of Scottish referral patterns to be a useful addition and note

their conclusions that pulmonary endarterectomy referrals have dramatically increased in parallel to the activity of their unit to be convincing. Importantly they include data from 2007–2008, which was not collected in our original cohort and this additional data clearly shows an increased referral rate. This is in line with our central hypothesis that referrals increase with local experience and awareness of the disease and operation. We did not provide an individual year on year breakdown as the numbers would be too small for statistical analysis; however, we agree that those regions with lower referral rates in the early years are now referring more.

The original analysis included only those patients who were operated on in an attempt to prevent bias, in particular to our own unit. As it is policy at Papworth Hospital (Cambridge, UK) for all CTEPH patients to be discussed at our multi-disciplinary team meetings this would invariably have led to our technically operable capture being higher than other units. As the service has expanded we have encouraged all centres to refer all patients with CTEPH for discussion.

We therefore still believe that the actual operable disease is the fairest end-point for this analysis, and ultimately is also the

most important measure of the implementation of the national programme.

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None declared.

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- 1 Toshner M, Suntharalingam J, Goldsmith K, *et al.* Current differences in referral patterns for pulmonary endarterectomy in the UK. *Eur Respir J* 2008; 32: 660–663.

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