

The advantage of a shared care service in improved access to pulmonary hypertension therapy for adult congenital heart disease associated pulmonary hypertension.

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Background. Historically, pulmonary hypertension management has been delivered in the UK by the National Pulmonary Hypertension service centres (NPHS). However, many regions are geographically removed from such centres making it difficult for patients with adult congenital heart disease associated pulmonary hypertension (ACHD-PH) to receive therapy. This is especially true if there are associated learning difficulties such as Trisomy 21.

Methods. We reviewed our clinics run as a shared care with an NPHS centre since 2008 to current date to determine the effect on access to therapy. We measured the mileage and uptake of therapy per head of population for remote areas of the UK covered by our clinic.

Results. 235 new patients were seen, with mean (sd) age 45 (19) years, 98 (42%) were male. Almost all had ACHD-PH with only 7.9% of patients with chronic thromboembolic pulmonary hypertension and 7.1% with idiopathic pulmonary arterial hypertension. 29.9% had learning difficulties. A full range of diagnostic facilities were present locally, the patients rarely having to travel to the NPHS centre. For therapy, 54.3% have been treated with single medication, 40.94% dual therapy and 13.4% on triple therapy compared to 59.4%, 36.5% and 14.9% respectively in the national database. A higher proportion of those on therapy (55.1%) received Endothelin receptor antagonist (ERA) therapy compared to 32.5% nationally and 58.0% receiving phosphodiesterase inhibitors vs 63.0% nationally. The number of our patients on therapy per 100,000 population increased from 0.7 to 4.7. The average mileage for clinic attendance was 48.8 miles compared with 163.7 miles if the journey had been made to the nearest NPHS centre, saving an average of 115 miles (3 hours of travelling for each clinic) and the cost of taxi fares to the NHS of £108,000.

Conclusion. We have shown that our clinic achieves the national average for the number of patients on therapy. The increased proportion of patients on ERA is due to the increased numbers of patients with ACHD-PH. The clinic improves access to disease modifying therapy and improves the ease of access to clinic for patients with learning difficulties whilst saving the NHS significant costs.