

Report to CTAG Lungs – May 2024

1. Introduction

- 1.1 This report outlines the key work undertaken by the CTPG Chair, CTPG members and CTPG meetings since the last CTAG Lungs meeting.

2. Patient Feedback

- 2.1 The most recent patient feedback gathering exercise can be seen in Appendix 1.

3. Adult Cardiothoracic Funding Mechanism

- 3.1 The CTPG are extremely concerned with the proposed single adult cardiothoracic transplant tariff (currently a guide price). The tariff appears to include assessment, preoperative stay, operative costs, post operative stay, and the cost of the long-term VAD service (excluding devices).
- 3.2 The CTPG Chair has written a letter to NHSE outlining concerns (see Appendix 2). As can be seen from the letter, the number of concerns is wide ranging. One of the major concerns is that a single tariff fundamentally undermines the cornerstone of the funding regime which is sufficient granularity to account for variation in patient complexity and disability.
- 3.3 The CTPG would strongly advocate for tripartite working between cardiothoracic transplant clinicians, patients and NHSE to ensure the adult cardiothoracic funding regime is fair for all centres and patient groups and is fit for purpose.

4. NICE Appraisal of Ivacaftor–tezacaftor–elixacaftor, tezacaftor–ivacaftor and lumacaftor–ivacaftor for treating cystic fibrosis

- 4.1 Following the publication of the draft NICE guidance for CFTR Modulator Therapies in November 2023, the CTPG submitted a consultation response (Appendix 3).
- 4.2 The Cardiothoracic Transplant Patient Group strongly supports continued access to CFTR Modulator Therapies for all clinically appropriate people with Cystic Fibrosis.

5. Other Key Engagement and Representation

- 5.1 Engagement across the country has continued with the CTPG Chair attending various support group meetings and regularly liaising with related charities and stakeholders.
- 5.2 Many CTPG members and other cardiothoracic transplant patients continue to be actively involved in promoting organ donation.
- 5.3 The CTPG continues to be a formal stakeholder in NICE appraisals relating to Covid prevention, treatment, and processes. Details can be viewed in a dedicated report.

5.4 The CTPG Chair attended the NHSE Annual Review Meeting for adult and paediatric cardiothoracic transplantation in November 2023 and January 2024.

5.5 The CTPG Chair has written to the CTAG Lungs Chair with follow up questions / concerns arising from the 2022/23 Annual Lung Transplant Report (30 November 2023) A responses has yet to be received.

5.6 The CTPG Chair, other cardiothoracic transplant patients and stakeholder organisations are engaged and actively involved in ISOU work at all levels.

6. CTPG Meeting 25 October 2023

6.1 The CTPG last met on 25 October 2023, the minutes are shown in Appendix 4.