

Report to CTAG Lungs – July 2023

1. Introduction

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

2. Patient Feedback

2.1 The routine patient feedback gathering exercise will be conducted shortly and presented at the next CTAG Lungs meeting.

3. Engagement and Representation

3.1 Engagement across the country has continued with the CTPG Chair attending various support group meetings and regularly liaising with related charities and stakeholders.

3.2 The CTPG Chair attended the joint NHSBT / BTS Conference in March 2023. Lay members / volunteers felt that the restrictions in place to reduce commercial / patient interaction considerably detracted from the ability to gather greatest benefit from the event.

3.3 The CTPG has become a formal stakeholder in NICE appraisals relating to Covid prevention, treatment, and processes. Details can be viewed in a dedicated report. A lung transplant recipient (also the Chair of Action for Pulmonary Fibrosis) has been a patient member on some NICE appraisal committees relating to Covid prevention treatments.

3.4 Four lung transplant recipients completed for Great Britain at the World Transplant Games in Perth, Australia, all successfully won medals.

3.5 The CTPG Chair submitted a formal response to the NHSE consultation on proposed commissioning changes which included significant changes to funding mechanisms for lung transplant services. The response can be seen in Appendix 1.

3.6 The CTPG Chair attended as an expert panel member the OUG Conference in May 2023.

3.7 The CTPG Chair has provided support to Dr Sam Kennedy and Professor Fisher with the wording and circulation of the patient survey to facilitate changes to the lung allocation policy. The survey generated 99 responses from patients / families.

3.8 The CTPG has circulated details of the ECLAD – UK Trial to the patient population.

4. CTPG Meeting 7 December 2022

- 4.1 The meeting witnessed a large attendance, the minutes are yet to be updated to the NHSBT website.
- 4.2 The meeting received update reports from both CTAG Chairs, ODT Medical Director, Senior Statistician, NIHR BRTU Director, OUG Executive Lead and CTPG Chair. The statistical report included new information on long term and conditional survival for adult heart transplant and agreed to produce the same for paediatric heart and lung transplants.
- 4.3 Pre-publication headline figures from the NHSBT led Covid 19 vaccine effectiveness study in solid organ transplant recipients were presented.
- 4.4 The group discussed the various NICE appraisals relating to Covid prevention and treatments. The CTPG consultation submission related to Covid therapies was approved and devolved responsibility for other submissions were also granted.
- 4.5 The group received an update from the Routine Bloods Working Group including the results of the patient survey.
- 4.6 An outline was given to the group of the programme of research to establish PROMs and PREMs in transplant care.
- 4.7 An update on the continued efforts to increase psychology resources was discussed and an audit of social work provision was agreed as concerns were raised by both professionals and patients regarding disparity of provision.
- 4.8 The next meeting has yet to be arranged. The CTPG Chair, patient community and other key stakeholders are extremely disappointed at the decision by NHSBT to reduce the CTPG meetings to one per year.