

Report to CTAG Hearts – May 2023

1. Introduction

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

2. Patient Feedback

2.1 The routine patient feedback gathering exercise will be conducted shortly and presented at the next CTAG Hearts 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 British Society for Heart Failure Annual Meeting in December 2022.

3.3 Three heart transplant patients / carers attended the joint NHSBT / BTS Conference in March 2023 with one patient an invited speaker. 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. The relative lack of heart related topics was also noted.

3.4 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.

3.5 Seventeen heart transplant recipients including 3 children competed for Great Britain at the World Transplant Games in Perth, Australia.

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

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 was 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.