

## Report to CTAG Lungs – Sept 2022

### 1. Introduction

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

### 2. Patient Feedback

2.1 Every 6 months patient support groups of all types are asked if they wish to provide feedback about the key issues patients are concerned about / discussing.

2.2 The feedback is extremely rich, and, in most cases, the same issues are being replicated across each group.

2.3 The following boxes summarise the key themes and issues from the feedback received

#### General

The cardiothoracic transplant pathway is an extremely difficult and traumatic process that frequently leaves people with significant ongoing mental and physical challenges. These continue post-transplant and include issues such as vulnerability, medication side effects, ongoing comorbidities, living with reduced mortality expectations and post traumatic symptoms.

This challenge is made harder by it not being recognised by any aspect of society, often this includes family, friends, and transplant centres.

Patients have a perception they need to show an upbeat public face as they have been given the “gift of life”, but their experience is very different.

#### Covid

Covid experiences are variable. Patients are very grateful for the vaccine program, and many have experienced timely effective treatments. However, this experience is not uniform, and many have experienced challenges with accessing accurate information, vaccines, tests, and appropriate treatments and advice. Many patients are disappointed with the national decision on Evusheld.

#### Primary Care

There is widespread concern about the quality and access of GP services. A large proportion of patients consider that GPs are ill equipped to deal with cardiothoracic transplant patients who often appear ignorant of typical transplant issues and are unwilling to proactively engage with specialist centres. Patients are really struggling to access GPs

#### Psychology Support

Many patients are reporting psychological challenges and a lack of specialist resources in transplant centres. There is also widespread reporting of the psychological challenges being faced by family, with no support being available.

## **Information for Cardiothoracic Transplant Patients**

Many patients are reporting a lack of information for their needs. Information is either non-existent, inconsistent, or not being updated. Patients are instead turning to information provided in other countries and by other patients

### **Communication**

Some patients report communication difficulties from and to their specialist centre. Some centres are difficult to contact and their provision of information to other clinical teams and patients can be slow and inaccurate.

### **Financial Impact and Support**

It is often reported that many post-transplant patients find financial benefits are terminated, despite having ongoing challenges which restrict their ability to earn.

## **3. Engagement and Representation**

- 3.1 Engagement across the country has continued and routine communication links have been established with 22 stakeholder charities and support groups.
- 3.2 The CTPG Chair regularly attends support group meetings to gather first hand intelligence of the generic issues regularly faced by patients and to provide feedback on key issues.
- 3.3 All stakeholders are given the opportunity to raise any generic issues with the CTPG Chair.

## **4. CTPG Meeting 22 June 2022**

- 4.1 The meeting witnessed a record attendance with over 40 participants, minutes can be seen in following link ([ctpg-m-22-01-to-be-ratified.pdf \(windows.net\)](#))
- 4.2 The meeting received update reports from both CTAG Chairs, OTDT Medical Director, Senior Statistician and CTPG Chair.
- 4.3 The meeting agreed to establish a working group to review the current processes for routine blood tests in post-transplant patients.
- 4.4 A Consultant Psychologist and CTPG Chair presented detailed reports including a patient survey reviewing the psychological support offered to patients. The reports revealed psychology provision to be insufficient in most centres. Many service standards were not being met and large numbers of patients were reporting that their psychological needs were not being met.
- 4.5 The report recommended a new standard of 1WTE psychologist per 350 patients, this recommendation was accepted.

4.6 The CTAG Lungs Chair delivered a presentation on Covid in the immunosuppressed

4.7 The Head of Transplant Development delivered a presentation about Change Board Projects including patient information on the NHSBT website and risk communication tools.

4.8 The next meeting is 7 December 2022.