Adult Cardiothoracic Transplantation

General Comments

1) **Lack of granularity which could lead to patients with certain protected characteristics (and the providers that treat them) being disadvantaged.**

The proposal for single tariffs for heart and lung transplants lacks the granularity needed to consider the underlying case mix and complexity variations among different patient groups, as well as the providers who may treat higher-than-average proportions of more complex patients.

The consultation process includes an Equality Impact Assessment (2025/26 NHS Payment Scheme – a consultation notice. Part C Impact Assessment). This document includes the following statement.

“The HRG4+ phase 3 currency design enables us to distinguish between care provided to patients with different levels of complexity to reflect the expected higher use of resources to treat patients who do have complications and comorbidities. Comorbidities can be associated with disability, and therefore this currency design helps to ensure that providers are more appropriately reimbursed for providing care to patients with disabilities. We are not aware of any other information that would suggest that the 2025/26 NHSPS proposals would have a disproportionate impact on this group of patients.” (Point 82 - Section 4.3.8)

By using single “package” tariffs for heart and lung transplant the benefit of the currency design which is intended to account for case mix differences is negated. As such the proposed cardiothoracic transplant tariff may discriminate between patients with protected characteristics. Providers maybe unwilling to take on more complex cases which incur additional resources, thus further discriminating against people with protected characteristics.

There is sufficient evidence within the publicly available information to suggest case mix differences between providers.

For example, congenital heart disease is a known risk factor for heart transplantation as it leads to longer waiting times (due to higher antibody presence), increased surgical complexity and prolonged recovery times. These are all key drivers of cost. Reimbursement of heart or lung transplants at a single tariff will disadvantage providers who treat an increased proportion of these patients. In 2023/24 the range of congenital heart patients between providers was from 0% to 41% of patients.

NHS England must conduct a full equality impact assessment of the proposed tariffs for heart and lung transplant to ensure that they do not discriminate against any protected characteristic. Discrimination could occur where a provider treats an above-average proportion of patients with a specific disability that is associated with increased complexity. This equality impact exercise needs to be developed in collaboration with expert clinical and patient representatives.

2) **Over emphasis on quantity, and a lack of commissioning for quality**

The patient body supports the aim of proposals to increase organ utilisation and transplant rates as there is unmet need evidenced by high waiting list mortality and poor transplant rates in comparison to much of the developed world.

It has been made clear in multiple fora, including through the Cardiothoracic Information Collation Exercise, that patients and families value quality of care, and the very direct impact it has on their quality of life. The patient body would therefore emphasise the need to also ensure payment mechanisms for cardiothoracic transplant, encourage and reward quality. With quality being assessed by multiple metrics, such as multi professional resourcing levels, mortality, morbidity and patient reported outcomes and experience.

The patient body would support the development of best price tariffs on this basis and would welcome the opportunity to engage in this process.

3) Impact of changes at a provider level

The significant change of funding mechanisms for cardiothoracic transplant are likely to have a negative financial impact on some providers. This has the potential to reduce quality of care provided by those centres. The patient body would recommend that any providers with financially negative impacts are “cushioned” with a multi-year transition period to ensure that providers can reengineer services without having a negative impact on patient care.

4) Lack of recognition of the financial impact of extreme cost patients

The costs of providing any acute service are significantly impacted by a small number of extreme cost patients. For cardiothoracic transplantation, costs will be largely driven by extreme lengths of stay, especially those in critical care facilities. The general construct of the payment mechanism recognises this by each HRG having a trim point (with excess bed days charged in addition) and critical care bed days being charged separately. The consultation document suggests that cardiothoracic transplant is a fixed package price. This is in direct contrast to the general principle of payment mechanisms for the overwhelming majority of other services and is especially concerning in high cost, high complexity, low volume activity such as cardiothoracic transplant.

5) Lack of acknowledgement and potential impact of services commissioned by NHSBT

The providers ability to deliver cardiothoracic transplant is entirely dependent on the retrieval of organs which are commissioned by NHSBT. If there were any significant changes in this provision it would impact on the providers ability to deliver transplant activity, and hence the funding they receive. Such examples could include the change in funding and hence provision of technologies to support organ retrieval such as the Organ Care System (OCS) for heart transplants and ex-vivo lung perfusion (EVLP) for lung transplants.

The patient body consider that increased integration and collaboration in commissioning transplant services between NHSBT and NHSE would lead to improved patient outcomes.

This theme was also highlighted in the DHSC Report; Honouring the gift of organ donation: utilising organs for transplant, with specific recommendations (No 12).

6) Lack of congruency with national strategic aims in organ transplantation

The Organ Donation and Transplantation 2030: Meeting the Need Strategy has a specific objective to ensure “recipient and transplant outcomes will be amongst the best in the world”. It is known that the UK outcomes do not compare favourably with comparable countries. For example, comparing UK adult lung transplant median survival and conditional survival against worldwide data from the International Society for Heart and Lung Transplantation the UK is below the average (NHSBT, 2023).

The patient body believes that NHS England need to ensure that tariffs are uplifted from the current cost basis to enable providers to deliver services which meet the strategic outcome aims.

Section 304 (Annex DpB: Guidance on currencies) accurately states the following, “the UK has poor rates of both lung and heart transplantation, compared to other countries, with many patients dying or being removed from the list within a year of being listed for a transplant; there therefore remains a substantial unmet need for transplant.” However, section 313 states there should be an allowance for “modest growth in transplantation rates”.

To address the recognised “substantial unmet need”, the patient body believes that NHSE must plan and fund for a substantial growth in cardiothoracic transplant activity.

7) Appropriate funding for patients with VADs who do not proceed to transplant.

The patient body recognise that long term VADs are solely commissioned as a bridge to transplant / decision. However, there will always be some patients with a long-term VAD who never proceed to transplant.

The patient body are concerned that this patient group will be disadvantaged as there is no clear funding stream for providers to provide the complex ongoing care they require. There are currently approximately 300 patients in the country with long terms VADs with nearly half of these not on the transplant waiting list. This number is likely to grow further and hence the lack of direct funding for this patient group will grow larger.

8) Low follow up tariff

The guide price annual follow up tariff of £4,061 (before MFF) appears to be extremely low. The closest comparable lifelong tertiary follow up service is cystic fibrosis. The lowest complexity (CYF1_) annual follow up tariff in cystic fibrosis is £6,304. The description of the expected specialist centre interaction with this complexity of patients is minimal (2/3 outpatient appointments per year and oral medication).

The required annual follow up after cardiothoracic transplant is extremely variable but the very minimum levels would probably be comparable to the lowest complexity cystic fibrosis patients. The proposed single cardiothoracic transplant follow up tariff does not seem credible.

As an example, in 2023 the Cardiothoracic Transplant Patient Group (CTPG) worked with the Psychology Association for Cardiothoracic Transplant to investigate whether the provision of specialist psychology services met patient’s needs.

The report demonstrated that in most centre’s the patient’s psychological needs were not being met

Additionally, the CTPG have led pieces of work reviewing the management of routine blood test processes and osteoporosis monitoring and management. Both have demonstrated widespread deficiencies in services provided by transplant centres.

Transplant centres have cited insufficient funding as a key factor.

In summary, patient body does not believe the proposed annual follow up tariff is sufficient to enable units to deliver safe, high quality lifelong post-transplant care. Insufficient follow-up care funding will lead to poor management of medical conditions associated with transplant recipients including the impact of long-term immunosuppression.

Specific Comments

1) **Lack of clarity and inconsistency over what is included and excluded from transplant tariffs?**

Section 317 (Annex DpB: Guidance on currencies) states that included in the transplant tariff is “patient assessment and immediate post operative care”, whilst in section 319 (Annex DpB: Guidance on currencies) states “patient assessment, immediate transplant preoperative care, post-transplant critical care”

These statements are clearly not fully aligned. There are so many potential different elements of care in the cardiothoracic transplant pathway across numerous points of delivery, and specific detailed guidance is required.

What is “immediate transplant pre-operative care”, does the word immediate refer to a specific time frame. Most heart transplant patients are in hospital prior to transplant, sometimes for many months, would this be included in the term immediate? The statement also indicates that post-transplant inpatient care following discharge from critical care is not included in the tariff. How is this part of the transplant pathway funded?

Failure to provide this and ensure congruency with the construct of the tariff will lead to local interpretation. It also has the potential to under resource Trusts which will lead to the inability to provide services.

2) **Lack of information over what is included and excluded from the annual follow up tariff**

The consultation document provides no information or guidance on what activity should and should not be included in the follow up tariff.

Failure to provide this and ensure congruency with the construct of the tariff will lead to local interpretation. It also has the potential to under resource Trusts which will lead to the inability to provide services.

3) **Lack of information on the reimbursement mechanisms for patients who do not proceed to transplant.**

There will inevitably be several patients who transverse some of the transplant care pathway but never proceed to transplant. The consultation document gives no information or guidance on how providers are reimbursed for these patients.

Failure to provide this and ensure congruency with the construct of the tariff will lead to local interpretation. It also has the potential to under resource Trusts which will lead to the inability to provide services.

4) Lack of formal rehabilitation post discharge

The 2025/26 NHS Payment Scheme unbundled tariffs include prices for cardiac and pulmonary rehabilitation for a specific defined list of dominant spell procedures and diagnosis; namely, acute MI, PCI, Heart Failure, CABG and COPD (8.1 & 8.2 Annex DpB: Guidance on currencies). All patients who have a heart and or lung transplant will attract an alternative dominant spell hence will not be eligible for post discharge rehabilitation.

The body of international evidence would strongly support the routine use of post discharge cardiac or pulmonary rehabilitation for transplant patients. As an example, this is a recommendation in the ISHLT Guidelines for the care of heart transplant recipients (2023).

Why are heart and / or lung transplant recipients not included in the list of eligible patients for cardiac or pulmonary rehabilitation?

5) Lack of detail in adult cardiothoracic transplant tariffs compared to renal

The specific comments section outlines the lack of detail provided about what is and is not included in the cardiothoracic transplant guide prices.

In comparison, renal transplants which are another guide price, provide much greater detail in Section 17 Annex DpB: Guidance on currencies. Similar detail and clarity are required for cardiothoracic transplants.

Summary

The patient body believe the proposed adult cardiothoracic transplant tariff is not fit for purpose. We have tried on repeated occasions to engage with the NHSE Pricing Team on this matter and have never received a response.

NHSE are currently undertaking a Cardiothoracic Transplant Transformation Programme and the patient body would request that funding mechanisms are included as one of the enabling workstreams within the programme.