Sarah Watson, Commissioning Manager, Highly Specialised Services, NHSE

27 February 2024

Dear Sarah,

As you will recall I previously submitting a consultation response (Reference ANON-12WW-7149-6) to NHSE relating to the proposed changes in the funding mechanism for adult cardiothoracic transplant services.

The publication of an appropriate and accurate funding mechanism for adult cardiothoracic transplant services is one of the fundamental strands of ensuring patients receive high quality, equitable care. Frequently, we as patients, either individually, or as a group are faced with the response from providers that they are not funded for certain activities which relate to cardiothoracic transplant commissioned activity.

NHSE have updated the 2023/25 NHS Payment Scheme and whilst a couple of the issues I raised have been revised most of the concerns remain.

At the NHSE Annual Adult Cardiothoracic Transplant Meeting on 20 November 2023, Jonas from the Pricing Team attended to give an update on tariff developments.

It was apparent from the discussions that the clinical engagement had been with the associated CRG Chairs, who may not be best placed to understand the unique and differing patient pathways for adult cardiothoracic transplant services. The meeting discussion also highlighted that some key aspects of the patient pathways (such as MDT assessment meetings) may not be fully covered in the package guide prices.

On 24 November I followed up this discussion with an email to you outlining the willingness of Jas, Venkat and myself to work with NHSE HSS and Pricing teams to ensure the tariffs and accurate, fair, and appropriate. The impression I had taken away from the meeting on 20 November was that this was the agreed way forward. I also requested a copy of the presentation given by Jonas at the meeting, which I have yet to receive.

Having not received a response from you, I send a reminder email on 31 December 2023. You replied the same day stating that you “understand from the pricing team that they will be picking this work up in the New Year”

I followed this with a further email on 22 January 2024 stating that Jas, Venkat and I were keen to take this work forward.

You replied on 2 February stating that the pricing team were busy working through the feedback from the recent consultation on proposed amendments to the 2023/25 NHS Payment Scheme.

I remain extremely concerned that the adult cardiothoracic transplant tariffs have several outstanding areas of concern to be addressed. To ensure that the tariffs are fair, equitable and fit to deliver the strategic objectives of the Organ Donation and Transplantation 2030: Meeting the Need (2021) and the Recommendations of the Report from the Organ Utilisation Group (2023) urgent clinical and patient involvement is needed to validate the tariffs.

I will go through each of the concerns raised in the consultation response to assess which remain outstanding.

Reviewing the comments raised in the CTPG consultation response (presented below in italics)

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 of single tariffs for heart and lung transplants do not have the granularity to account for underlying case mix and hence complexity differences between different patient groups and the providers that may treat above average proportions of more complex patients.

The consultation process includes an Equality Impact Assessment (2023/25 NHS Payment Scheme – a consultation notice. Part C Impact Assessment, Section 4). 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 2023/25 NHSPS proposals would have a disproportionate impact on this group of patients". (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 lost. As such the proposed cardiothoracic transplant tariff may discriminate between patients with protected characteristics.

There is sufficient evidence within the publicly available information to suggest this is indeed the case.

For example, previous open-heart surgery 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 transplants at a single tariff will disadvantage providers who treat an increased proportion of these patients. Analysis of the last 3 reported years transplant registrations show a range between providers from 18% to 57% of patients who have had previous open-heart surgery.

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 the case mix with a specific disability that is associated with increased complexity. This equality impact exercise needs to be developed in collaboration with clinical and patient representatives.

This remains an area of significant concern with the lack of granularity highly likely to lead to discrimination of patients with certain protected characteristics. As a further example NHSBT have recently analysed the proportion of urgent heart transplant patients waiting over 6 months by diagnostic group. This has revealed that 25% of congenital disease patients wait over 6 months for an urgent heart transplant compared to an average of 8% for other diagnostic groups. Most congenital heart transplants are conducted by one provider. If the preoperative stay for an urgent heart transplant is included in the package guide price this will significantly skew provider costs against an equal reimbursement.

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

The CTPG 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.

However, the CTPG would 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 CTPG would support the development of best price tariffs on this basis and would welcome the opportunity to engage in this process.

This issue does not appear to have been addressed with activity remaining the sole mechanism for reimbursement.

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 CTPG 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.

You informed me that during 2023/24 baseline cardiothoracic transplant funding would be protected through the API funding mechanism. However, in future years variations from baselines may occur. It would be helpful for an update on these plans.

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.

This issue has not been addressed and remains a significant concern.

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 CTPG 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). This concern remains outstanding and any significant change to the provision of organs will clearly lead to a fixed priced tariff becoming inaccurate.

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

The commissioning documentation references strategies which are out of date and have been superseded. Taking Organ Donation to 2020 has been replaced by Organ Donation and Transplantation 2030: Meeting the Need.

The updated 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 heart transplant median survival and conditional survival against worldwide data from the International Society for Heart and Lung Transplantation the UK is below the average (N Onwuka & S Rushton, NHSBT, 2022).

The CTPG 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 aim in terms of outcomes.

The 2023/25 NHS Payment Scheme has been updated to reference the up-to-date organ donation and transplantation strategy, however, there is no evidence that the tariff has revised to reflect the aims within the strategy. In 2023 CTAG Lungs also received information revealing that adult lung transplant median survival is below the worldwide average recorded by ISHLT.

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

The CTPG 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 CTPG 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.

This issue does not appear to have been addressed.

8) Low follow up tariff

The guide price annual follow up tariff of £2,388 (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 £5,762. The description of the expected specialist centre interaction with this complexity of patients is minimal (approx. 2 outpatient appointments per year).

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 it is less than half the lowest complexity cystic fibrosis follow up tariff.

As an example, in 2023 the 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 (CTPG June 2022, Burns & Malpus).

Transplant centres have cited insufficient funding as a key factor.

In summary, CTPG does not believe the proposed annual follow up tariff is sufficient to enable units to deliver safe, high quality lifelong post-transplant care.

The annual follow up tariff has been increased to £3,816, but this remains an area of significant concern. The comparison to the CF tariff (CYF1_ is £5,925) is extremely concerning.

Additionally, since the consultation response 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.

Providers often citing a lack of funding as a reason for the service deficiencies.

9) Potential to further disincentivise lung transplant in comparison to heart transplant

It has been reported that due to capacity constraints centres sometimes proceed with a heart transplant when they have also been offered donor lungs (Onwuka & Rushton, CTAG Lungs Sept 2022).

Most heart transplants undertaken are to patients in hospital, whilst most lung transplants undertaken are to patients waiting at home. Each day that a patient waits in hospital the cost to the provider increase. As the proposed transplant tariff reimburses a fixed amount per transplant there is a financial incentive for a provider to reduce in hospital pre transplant waits.

If a provider is faced with the choice between proceeding with a lung transplant for a patient waiting at home reimbursed at £92,584 (plus MFF) or a heart transplant for an in hospital patient reimbursed at £118,337 (plus MFF), from a purely financial perspective the heart transplant is the logical choice.

The CTPG is concerned that the proposed reimbursement mechanism of a fixed price inclusive tariff will further disadvantage lung transplant patients.

This issue has been addressed with lung and heart transplants now attracting the same guide price.

Specific Comments

1) Clarification over marginal rates

Section 282 states "the proposed currency and marginal payment rate". The word marginal implies that payments for additional (or reduced) activity units would be reimbursed at a figure less than 100%. NHS England Highly Specialised Services Team stated that reimbursement would be 100%. Please could this be clarified.

The published guidance on currencies (Annex B) uses the term variable (reference 286-287) which provides better clarification.

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

Section 292 states that included in the transplant tariff is "patient assessment and immediate post operative care", whilst in section 294 it states "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.

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.

The wording has been updated to state that the transplantation price includes patient assessment, immediate transplant pre-operative care, post-transplant critical care and remuneration for the LT VAD service (excluding the cost of the devices). This statement still lacks clarity, for example 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?

This issue remains unresolved.

3) **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.

This issue remains unresolved.

4) **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.

This issue remains unresolved.

New Comments / Issues

Following further examination of the 2023/25 NHS Payment Scheme in relation to adult cardiothoracic transplant further issues / areas for clarification have become apparent.

1) **Lack of formal rehabilitation post discharge**

The 2023/25 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. 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.

This may explain why I have had reports of transplanted patients being refused access to their local cardiac or pulmonary rehabilitation services, or indeed in most cases not being referred to them.

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?

2) 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 Annex B, see table 15 (pages 84-86). A similar table is required for cardiothoracic transplants.

As I have stated I would like to meet with the NHSE HSS and Pricing teams to discuss the construct of the adult cardiothoracic tariff and work through the areas of concern I have outlined. It would be essential to involve Venkat and Jas in these discussions and I am sure they would be willing to actively engage and provide valuable clinical insight.

Until this process occurs and is satisfactorily concluded, I do not have confidence that the current adult cardiothoracic guide prices and overarching funding mechanisms are able to provide sufficient, fair, equitable funding to the providers. The consequence of this is that services to patients will fall short of the required level of resource input leading to inadequate service access and quality, with inevitable inequities.

I look forward to hearing from you to arrange a meeting with the pricing team and yourselves to discuss these issues in detail.

With best wishes
Robbie Burns

Cardiothoracic Transplant Patient Group Chair
NHSBT

Copies to

Dr Ayesha Ali, Medical Advisor, Highly Specialised Services, NHSE

Fiona Marley, Head of Highly Specialised Commissioning, NHSE

Dr Parmar, Chair Cardiothoracic Transplant Advisory Group – Lungs, NHSBT

Professor Venkatswaran, Chair Cardiothoracic Transplant Advisory Group – Hearts, NHSBT

William Vineall, Co-Chair, Implementation Steering Group for Organ Uitilsation, DHSC

Professor John Forsythe, Co-Chair, Implementation Steering Group for Organ Uitilsation, DHSC

Jessica Jones, Cardiothoracic Transplant Patient Representative, Implementation Steering Group for Organ Uitilsation, DHSC