

Analysis of hospital activity and costs following allogeneic stem cell transplantation in England

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Contents

	Page
Executive summary	03
Introduction	04
Approach	06
Findings: the transplant spell	08
Findings: hospital activity	09
Findings: costs	11
Conclusion and recommendations	12
References and technical notes	13

Executive summary

In 2017 1,143 adults and 297 children in England received an allogeneic stem cell transplant. This is a potentially lifesaving treatment for people with blood cancer and blood disorders. Physical and psychological late effects (or 'long-term complications'), such as graft versus host disease (GvHD), are common.

The provision of post-transplant care varies substantially across the country. It has been suggested that this is partly due to the current payment model for stem cell transplantation: NHS England and NHS Improvement (NHSE/I) pay for services 30 days before and 100 days after stem cell transplantation, with services beyond this point largely paid for by c. 200 local Clinical Commissioning Groups (CCGs).

The lack of economic data relating to stem cell transplantation makes it difficult to understand how the current payment model may be driving variation and also hinders discussions about new payment models. The NHS Long Term Plan (NHS LTP) commits to exploring new payment models to help ensure that patients receive the right care, in the right place, at the right time.

To start filling this gap in the evidence base, EY was commissioned by Anthony Nolan to independently conduct an initial analysis of the hospital activity and costs associated with allogeneic stem cell transplant patients in the 365 days after discharge.

Two sources of data were used:

- ▶ NHS Digital's Secondary Uses Service (SUS) data, to identify patients who received an allogeneic stem cell transplant in England during 2015/16 and track any further hospital activity in the 365 days after discharge
- ▶ The Royal Marsden NHS Foundation Trust's (RMH's) Patient Level Information and Costing Systems (PLICS) data, to approximate the costs linked to this activity. RMH's PLICS data was adjusted using their Market Forces Factor (MFF) to reflect regional variation in costs.

Our key observations are as follows:

Hospital activity remained significant beyond 100 days. On average, between 100 days and 365 days after discharge, patients experienced 2 elective or non-elective inpatient spells (19 bed days, including 1.2 critical care bed days), 9 day cases or regular day attendances, and 20.2 outpatient appointments.

Costs also remained significant beyond 100 days. The costs incurred between 100 days and 365 days after discharge were £70.0mn nationally (30%) and £68,033 per patient (33%).

Despite the limitations of our analysis, which are explained in detail in this report, these findings suggest that the current payment model for stem cell transplantation may benefit from review. The 100 day cut-off does not reflect the fact that hospital activity and costs remain significant beyond this point.

Recommendations:

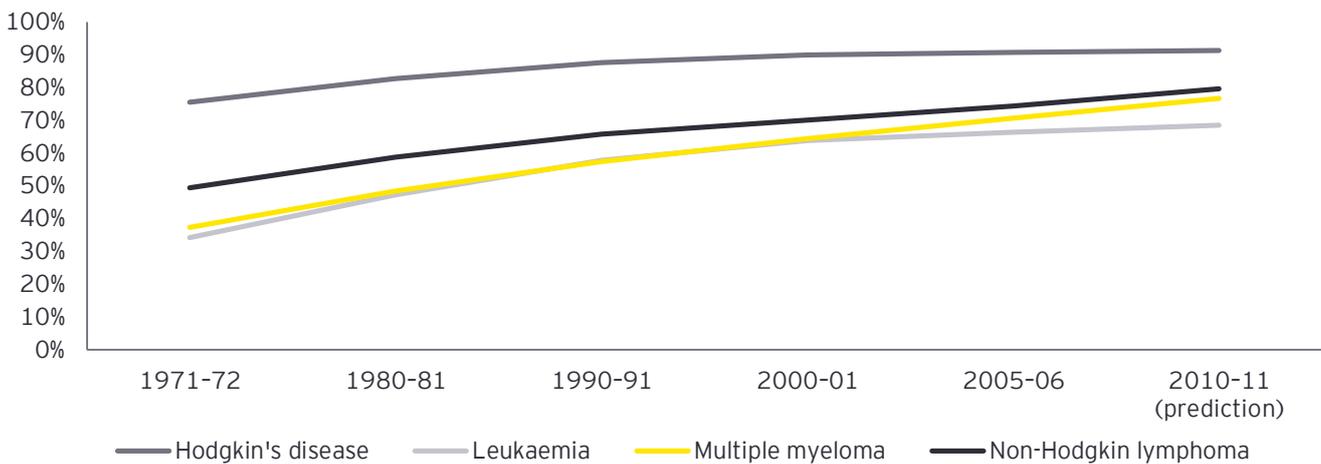
1. NHSE/I, in collaboration with providers, should explore the potential benefits of a new payment model for stem cell transplantation in line with the ambitions of The NHS LTP. They should also take steps to ensure that the underpinning data relating to hospital activity, costs - and income - is of the highest possible quality
2. Further research should be undertaken to answer the questions below. This is likely to depend on less restricted access to SUS, and an ability to link SUS to more detailed patient information such as registry data, GP data and ONS mortality data
 - a. What hospital activity, costs and income are associated with allogeneic stem cell transplant patients beyond the first 365 days after discharge (and what about activity outside of hospitals)?
 - b. How do hospital activity and costs vary by patient group, for example by age, original diagnosis, type of allogeneic stem cell transplant, GvHD status and/or socioeconomic background?
3. Further research should also be undertaken to explore how the post-transplant care pathway may help reduce hospital activity and costs. There is more than one way of doing this, but as a guide we recommend:
 - a. Partnering with a number of providers, including co-designing the research with them
 - b. Designing an approach to measuring the implementation of the pathway across providers
 - c. Comparing hospital activity and costs across providers, making sure to take account of key variables such as patient case mix

Introduction

What are blood cancers and blood disorders?

There are over 100 different types of blood cancer, the three main groups being leukaemia, lymphoma and myeloma [2]. It is the fifth most common cancer and the third biggest cancer killer; nearly 35,000 people are diagnosed with blood cancer and nearly 13,000 lives are lost to blood cancer every year in England. Survival rates vary by type, but have generally been improving over time [3].

One year survival by blood cancer type over time [3]



Blood disorders are a group of non-cancerous conditions, the most common of which are Myelodysplastic Syndromes (MDS); approximately 2,400 people are diagnosed with MDS every year in England. Other blood disorders include aplastic anaemia, sickle cell disease, autoimmune diseases and thalassaemia. Some blood disorders, like MDS, can develop into blood cancer.

What is an allogeneic stem cell transplant?

An allogeneic stem cell transplant is a potentially lifesaving treatment for people with blood cancer and blood disorders, which works by replacing damaged blood cells with healthy ones.

In an allogeneic stem cell transplant, the stem cells come from a donor (either a sibling donor, matched unrelated donor, cord blood donor or haploidentical donor). This is in contrast to an autologous stem cell transplant, where the patient's own stem cells are collected and returned to them [4].

Every year in England, approximately 1,100 adults and 300 children receive an allogeneic stem cell transplant. The total number is increasing at an average rate of 5% year-on-year. Adults most commonly receive an allogeneic stem cell transplant to treat blood cancer, whereas children most commonly receive an allogeneic stem cell transplant to treat a blood disorder.

What drives variation in the provision of post-transplant care?

Physical and psychological late effects (or 'long-term complications') are common after an allogeneic stem cell transplant. A major cause of morbidity and mortality is graft versus host disease (GvHD), where the donor's cells attack the patient's cells because it sees them as 'different'. GvHD affects approximately 30% to 40% of patients and can occur years after treatment [5].

The importance of long-term follow-up to prevent, manage and treat late effects is internationally recognised. Despite this, evidence shows that there is substantial variation in the provision of post-transplant care across the country, leading to inequitable access to treatment, care and support.

One driver of variation is the lack of a minimum standard for post-transplant care. The charity Anthony Nolan and an Expert Steering Group consisting of leading healthcare professionals, local NHS representatives and patients sought to address this by publishing 'A pathway for post-transplant care' in May 2019. The pathway describes the services and support packages that are central to patients' recovery.

Introduction (cont'd)

It has also been suggested, in discussions with healthcare professionals, that another driver of variation is the current payment model for (allogeneic and autologous) stem cell transplantation:

- ▶ The stem cell transplant itself, plus services 30 days before and 100 days after, are paid for by NHS England and NHS Improvement (NHSE/I) as part of their specialised commissioning responsibilities.
- ▶ Services beyond this point are largely paid for by c. 200 local Clinical Commissioning Groups (CCGs). The one exception is Extracorporeal Photopheresis (ECP), which is a treatment for GvHD of the skin. This continues to be paid for by NHSE/I.

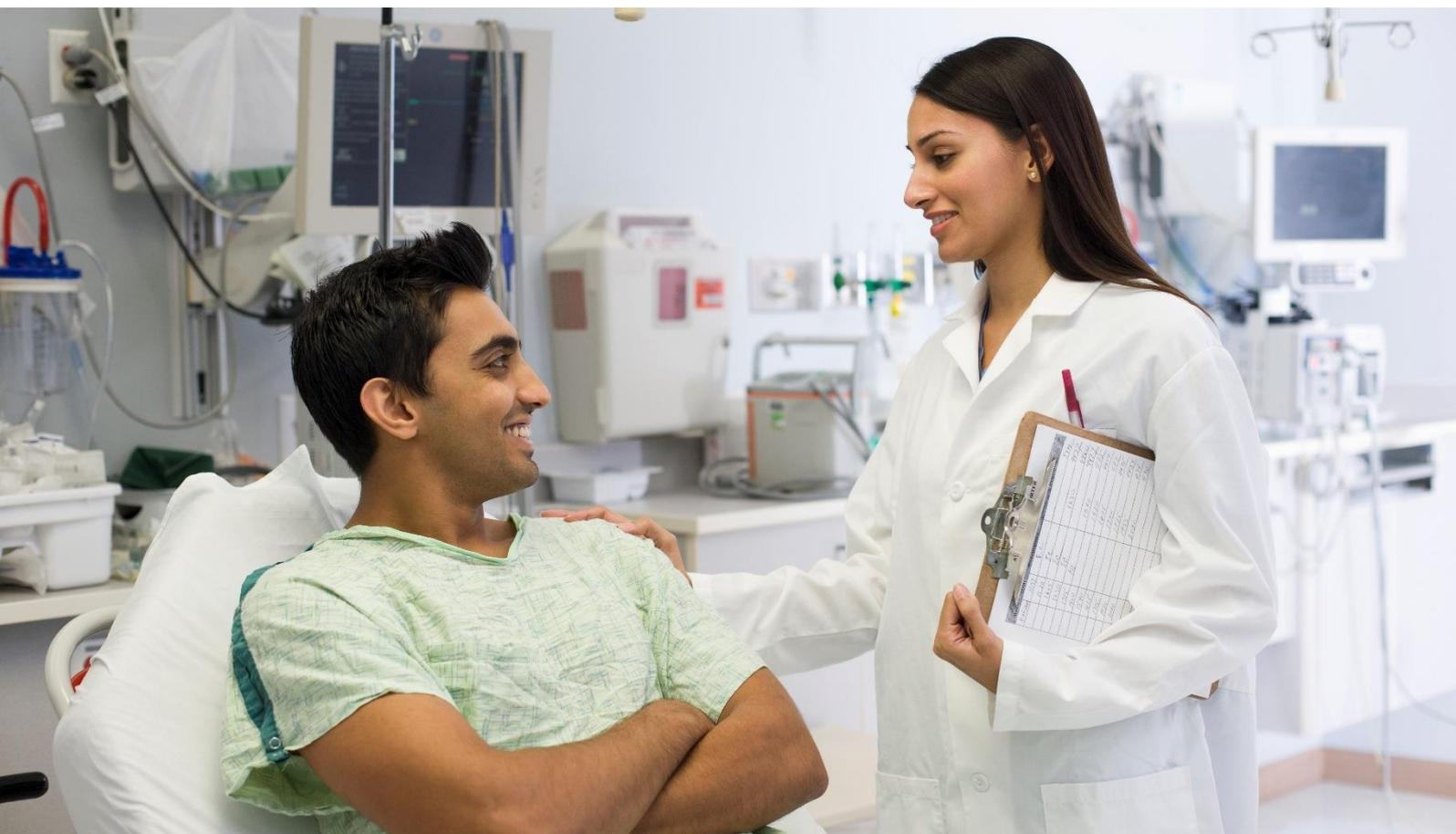
This is an example of an activity-based payment model, where providers receive a fixed amount of money for each 'unit' of activity they undertake.

What is the purpose of this report?

There is very little economic data relating to stem cell transplantation in the public domain. This makes it difficult to understand how the current payment model may be contributing to variation in the provision of post-transplant care across the country.

It also hinders discussions about new payment models that could, potentially, facilitate improvements in post-transplant care. The NHS Long Term Plan⁶ (NHS LTP) makes a general commitment to exploring new payment models to help ensure that patients receive the right care, in the right place, at the right time. There is a focus on moving away from activity-based payments to population-based payments, where providers receive a fixed amount of money based on the number of patients in a given population.

To start filling this gap in the evidence base, EY was commissioned by Anthony Nolan to independently conduct an initial analysis of the hospital activity and costs associated with allogeneic stem cell transplant patients in the 365 days after discharge. This report presents our findings and highlights areas where more research is needed.





Approach

Two sources of data were used to analyse the hospital activity and costs associated with allogeneic stem cell transplant patients in the 365 days after discharge: NHS Digital's Secondary Uses Service (SUS) data and The Royal Marsden NHS Foundation's Trust's (RMH's) Patient Level Information and Costing Systems (PLICS) data.

SUS data

When a patient is treated or cared for, information is collected that supports their treatment. This patient level information is stored in a secure data warehouse known as SUS. With permission, organisations can access SUS for 'secondary' purposes (purposes other than direct clinical care). This includes healthcare planning, development of national policy and research.

EY holds three years of pseudonymised SUS data from every trust in England. We were able to use this data to identify patients who had received an allogeneic stem cell transplant in 2015/16 and track any further hospital activity associated with these patients in the 365 days after discharge (up to a maximum end date of 31 March 2017).

PLICS data

SUS data is designed to enable payments for services on national tariff, and as such does not contain cost information for stem cell transplants (costs being as defined as those faced by providers to provide the service as opposed to commissioner spend on the service). We therefore worked with RMH, who provided access to their PLICS data (detailed PLICS data is not publicly available). This allowed us to approximate the costs linked to the hospital activity captured by SUS.

We recognise that RMH's costs are likely to be higher than those of their counterparts across the country. Reasons for this include increased capital, building and staff costs in London. In order to estimate national averages, we adjusted RMH's PLICS data using their Market Forces Factor (MFF), which is a measure of the unavoidable variation in costs between providers. MFFs are published by NHSE/I as part of the national tariff.

Strengths and limitations

Our approach was limited by:

- ▶ **Only tracking hospital activity for 365 days:** We had originally wanted to track hospital activity for 730 days (two years) after discharge. This was not possible because, at the start of 2017/18, NHS Digital changed the encryption key used for pseudonymisation. This created a break in the data, making it impossible to follow the same group of patients from 2015/16 and 2016/17 into 2017/18
- ▶ **Not knowing the exact date of a patient's allogeneic stem cell transplant:** In our SUS data, we could only see when a patient was admitted and discharged. This is why our analysis considers the 365 days after discharge (broken down into the first 100 days, the next 100 days and the 165 days after that), rather than the 365 days post-transplant. It means that we could not precisely align with the 100 days post-transplant paid for by NHSE/I
- ▶ **Calculating average hospital activity and costs:** We had restricted access to SUS (meaning that we could not extract data where the activity count went below five, to protect the anonymity of patients) and no access to more detailed patient information such as registry data, GP data and Office for National Statistics (ONS) mortality data. This prevented us from conducting subgroup analysis, for example patients with and without GvHD. Note that all averages provided in this report are weighted means
- ▶ **Relying on PLICS data from a single provide:** We recognise that adjusting RMH's PLICS data using their MFF can only account for so much of the variation in costs between providers. For example, we were not able to capture differences in models of care nor patient casemix

Despite these limitations, to our knowledge, no longitudinal analysis of post-transplant activity in England has been carried out in this much detail. We therefore believe that this report makes an important contribution to the evidence base. Technical notes can be found on p.14.

Approach (cont'd)

Step-by-step overview



Step 1: Within national SUS dataset identify all patients who had an allogeneic stem cell transplant in financial year 2015/16 (defined by dominant procedure OPCS codes). Apply data filtering and cleaning to refine cohort of patients, e.g., exclude any duplicate data, convert episodes to spells, etc.



Step 2: Segment the cohort to enable analysis. e.g., split by age group, centre of treatment, procedure code.



Step 3: Identify all hospital activity (by activity type, including inpatient, outpatient, day case, A&E and regular day attender) related to this same cohort of patients in the 365 days subsequent to their own original stem cell transplant spell, including activity which a) was undertaken at the same hospital where the transplant took place and b) was undertaken at another hospital.



Step 4: Cost the activity based upon a benchmarked cost per activity type (supplied by the RMH as an extract of their patient level costing and information system (PLICS) data). Arrive at an average profile of activity and costs for the pathway. Correct for the expected higher costs in London using Market Forces Factor.

Findings: the transplant spell

We identified 1,190 patients who received an allogeneic stem cell transplant in 2015/16, 60 of whom were treated at RMH. This varies from figures published by the BSBMTCT, who quote 1,440 transplants for 2017 [ref]. This difference is likely driven by use of different data sources, SUS including only patients treated for and by the NHS (not private patients) and our analysis focusing on first transplants.

The 'transplant spell' describes the period from admission to discharge. We found that patients had an average length of stay of 33 days, with younger patients having the longest length of stay. This is important because, as already highlighted, our analysis considers the 365 days after discharge rather than the 365 days post-transplants. It means that 100 days after discharge is roughly equivalent to 133 days post-transplant (and so on).

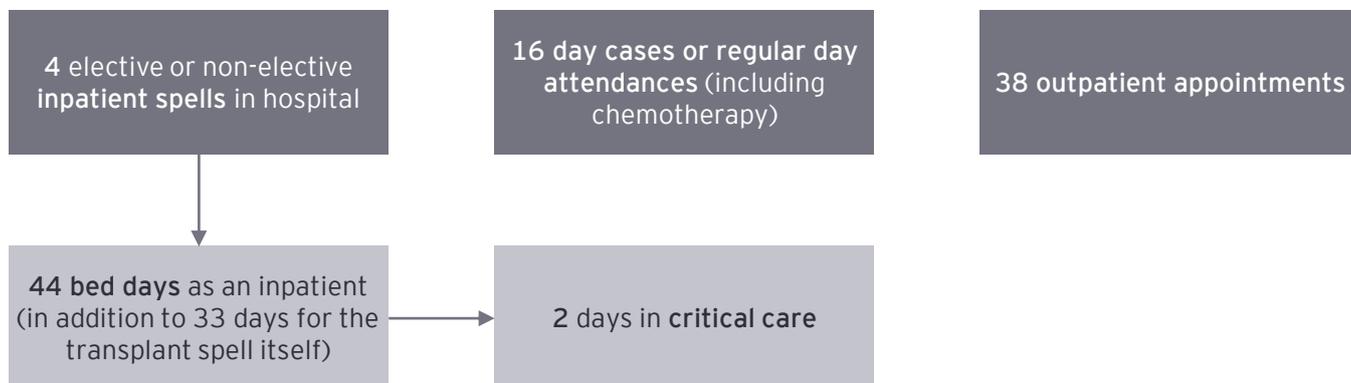
Age	Transplants (spells)	Average length of stay (ALOS)
65+	160	28.25
Adult (18-65)	899	30.63
Children	131	57.06
All ages	1190	33.22

While not a focus of this report, it is also worth noting that allogeneic and autologous stem cell transplants are very different treatments and, as a result, incur very different costs. For example, allogeneic stem cell transplants involve the work of finding a suitable donor (potentially from abroad) and are more likely to lead to late effects requiring additional management. However, in both cases, it is direct costs such as medical and nursing staff that are most significant. Overhead costs include back office support, building and utilities.

Transplant type	Direct costs	Overhead costs	Total costs
Allogeneic			
Adult	60,759	12,716	73,476
Children	93,122	20,608	113,730
Autologous			
Adult	11,730	4,899	16,629
Children	30,733	11,514	42,247

Findings: hospital activity

Using SUS data, we tracked survival and hospital activity for all 1,190 allogeneic stem cell transplant patients in the 365 days after discharge. This included activity beyond the hospital where they were originally treated. We found that, on average, a patient surviving the full 365 days after discharge experienced:



The diagram overleaf goes into more detail, showing survival and hospital activity at 100 days, 200 days and 365 days after discharge. A key observation is that, while hospital activity generally declined over time, it remained significant beyond 100 days with patients experiencing:

- ▶ 2 elective or non-elective inpatient spells (19 bed days, including 1.2 critical care bed days)
- ▶ 9 day cases or regular day attendances
- ▶ 20.2 outpatient appointments

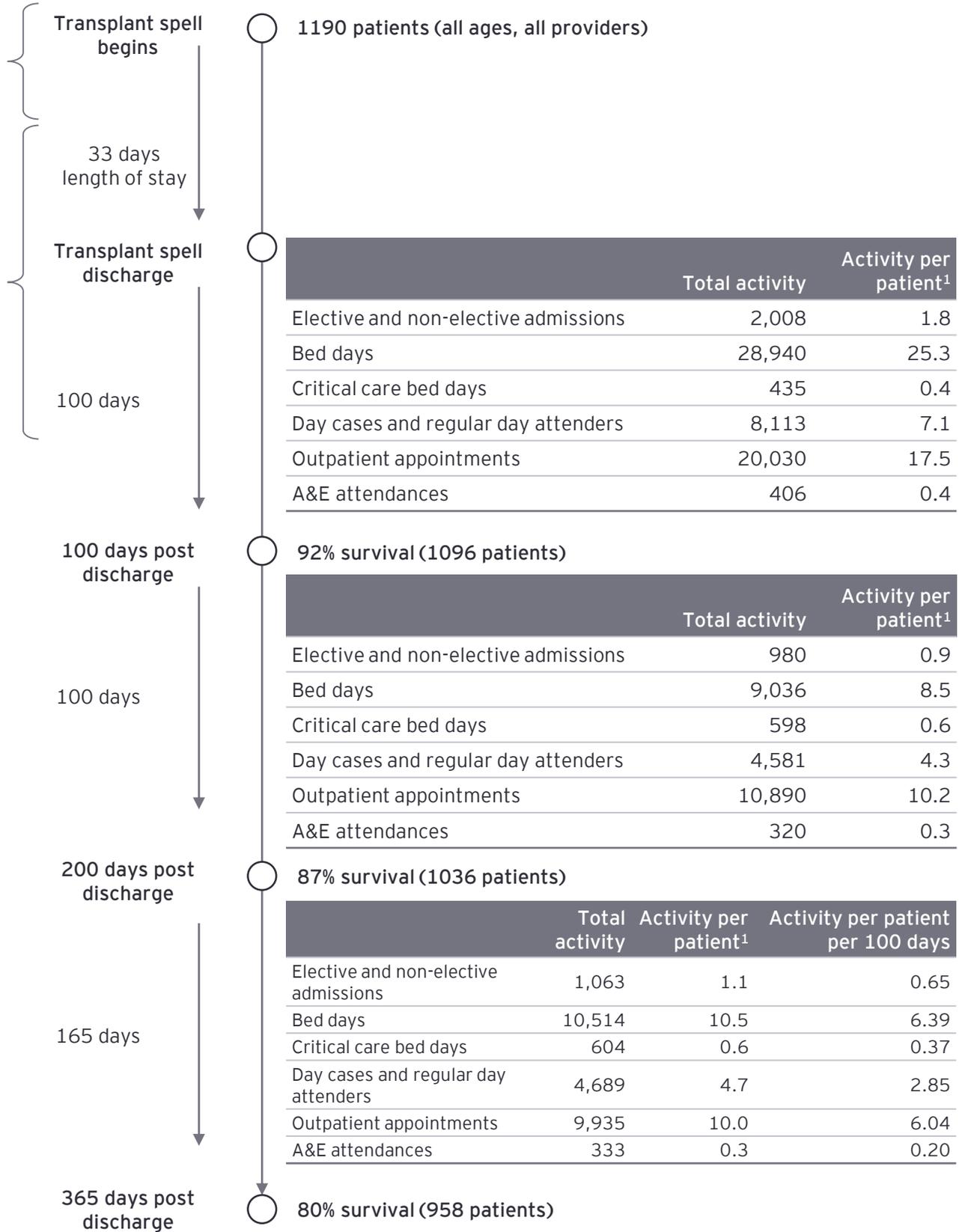
While we were unable to conduct subgroup analysis, it is fair to assume that hospital activity will vary depending on a wide range of factors including the patient's age, their original diagnosis and the severity of any late effects such as GvHD. It has previously been shown that patients with GvHD experience a higher number of inpatient spells than patients without GvHD.

We are also unable to say how much hospital activity was avoidable. This is a topical issue; for example, the NHS LTP⁶ commits to fundamentally redesigning outpatient services so that, over the next five years, patients will be able to avoid up to one-third of face-to-face outpatient appointments (equivalent to 30mn outpatient appointments every year).





Current package payment covers 30 days pre transplant and 100 days post transplant. As the transplant date itself is not present in our SUS dataset, we were unable to precisely align our analysis to these dates.



¹Based on average number of surviving patients across the period, calculated as = [activity #]/(0.5¹[surviving patients at start of period]+ 0.5¹[surviving patients at end of period])

Findings: costs

By combining SUS data with RMH's PLICS data, adjusted using their MFF, we were able to estimate the costs associated with the initial transplant spell plus the 365 days after discharge.

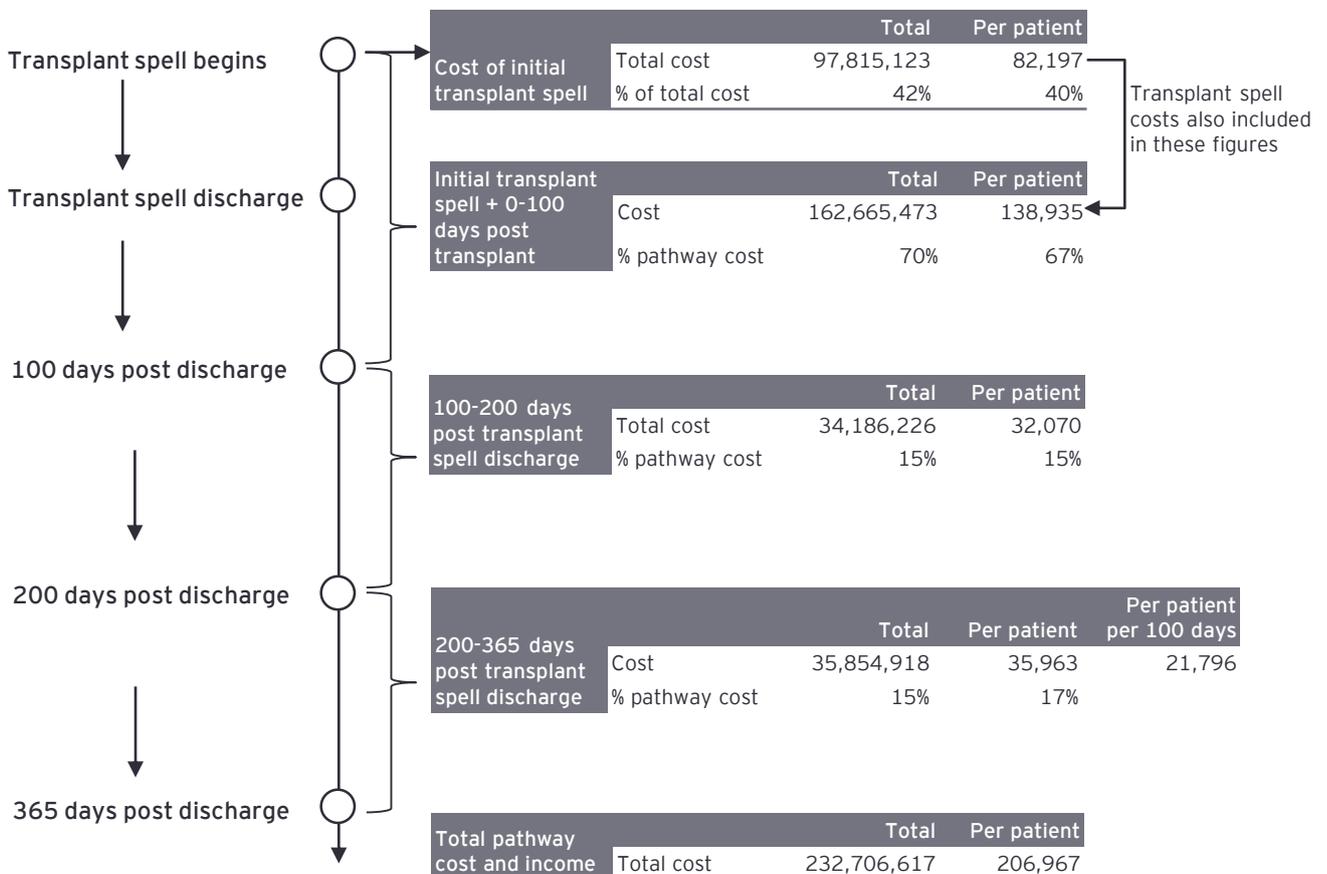
The diagram below shows that, nationally:

- ▶ Initial transplant spell cost £97.8mn (42%)
- ▶ 100 days after discharge cost £64.9mn (28%)
- ▶ 100 days to 200 days after discharge cost £34.2mn (15%)
- ▶ 200 days to 365 days after discharge cost £35.9mn (15%)

- ▶ Initial transplant spell cost £82,197 (40%)
- ▶ 100 days after discharge cost £56,738 (27%)
- ▶ 100 days to 200 days after discharge cost £32,070 (15%)
- ▶ 200 days to 365 days after discharge cost £35,963 (17%)

As with hospital activity, while costs generally declined over time, they remained significant beyond 100 days; approximately one-third of the total cost was incurred between 100 days and 365 days after discharge.

A similar breakdown of costs was seen for a patient surviving the full 365 days after discharge:



Conclusions and recommendations

This report presents an initial analysis of the hospital activity and costs associated with allogeneic stem cell transplant patients in the 365 days after discharge. We have demonstrated that much can be achieved using SUS data and PLICS data, and hope that our approach is of as much interest as our key observations.

Our key observations are that:

- ▶ Hospital activity remained significant beyond 100 days. On average, between 100 days and 365 days after discharge, patients experienced 2 elective or non-elective inpatient spells (19 bed days, including 1.2 critical care bed days), 9 day cases or regular day attendances, and 20.2 outpatient appointments.
- ▶ Costs also remained significant beyond 100 days. The costs incurred between 100 days and 365 days after discharge were £70.0mn nationally (30%) and £68,033 per patient (33%).

Despite the limitations of our analysis, these findings suggest that the current payment model for stem cell transplantation may benefit from review. The 100 day cut-off does not reflect the fact that hospital activity and costs remain significant beyond this point.

Recommendations:

1. NHSE/I, in collaboration with providers, should explore the potential benefits of a new payment model for stem cell transplantation in line with the ambitions of The NHS LTP. They should also take steps to ensure that the underpinning data relating to hospital activity, costs - and income - is of the highest possible quality
2. Further research should be undertaken to answer the questions below. This is likely to depend on less restricted access to SUS, and an ability to link SUS to more detailed patient information such as registry data, GP data and ONS mortality data
 - a. What hospital activity, costs and income are associated with allogeneic stem cell transplant patients beyond the first 365 days after discharge (and what about activity outside of hospitals)?
 - b. How do hospital activity and costs vary by patient group, for example by age, original diagnosis, type of allogeneic stem cell transplant, GvHD status and/or socioeconomic background?
3. Further research should also be undertaken to explore how the post-transplant care pathway may help reduce hospital activity and costs. There is more than one way of doing this, but as a guide we recommend:
 - a. Partnering with a number of providers, including co-designing the research with them
 - b. Designing an approach to measuring the implementation of the pathway across providers
 - c. Comparing hospital activity and costs across providers, making sure to take account of key variables such as patient case mix

References and technical notes

References

1. British Society of Blood and Marrow Transplantation and Cellular Therapy, document held on file by Anthony Nolan
2. <https://www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/what-blood-cancer>
3. [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(14\)61396-9/fulltext#tbl2](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)61396-9/fulltext#tbl2)
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5. Dignan FL et al, <https://www.ncbi.nlm.nih.gov/pubmed/23278853>
6. NHS Long term plan, <https://www.longtermplan.nhs.uk/>

Technical notes

- a. Market Forces Factor (MFF):** the MFF is an index, calculated by NHSE/I as part of the national tariff, which allows a provider's location-specific costs to be compared with every other organisation. It has a minimum value of 1.00. For our analysis of costs, we adjusted RMH's PLICS data using their MFF. RMH's MFF is 1.20 and the simple mean MFF across all providers is 1.08. We therefore multiplied RMH's costs by $1.08/1.20 = 0.90$ to estimate national averages. More information on the MFF can be found in NHSE/I's national tariff workbook: improvement.nhs.uk/resources/national-tariff/#h2-annexes
- b. Types of hospital activity:** elective inpatient spells are planned activities for which patients stay in hospital for one or more nights. Non-elective inpatient spells are unplanned activities for which patients stay in hospital for one or more nights. We have grouped together day cases and regular day attendances; these are both planned activities for which a patient is officially admitted to hospital, but does not stay overnight
- c. Costs:** costs have been calculated by subdividing hospital activity into categories (transplant spell, other elective and non-elective admissions, day cases and regular day attendances, and outpatient appointments) and then using adjusted RMH PLICS data to identify the corresponding costs for each 'unit' of activity. For example:

Total transplant spell costs = number of transplant spells x average transplant spell cost (as per adjusted RMH PLICS data)

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