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Contents

| | |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Introduction | 3 |
| How to access, use and submit the online form..... | 3 |
| Access and features of the online survey | 3 |
| User-friendly features..... | 3 |
| Error messages..... | 4 |
| Submission Guidelines | 5 |
| Saving Progress | 6 |
| Receive a copy of the submission | 6 |
| Centre address and team's information | 7 |
| Tables..... | 8 |
| Queries on the survey..... | 9 |
| Data protection..... | 9 |
| Questions and technical support | 10 |
| Other ways to participate in the survey | 10 |
| Participate in Satisfaction Survey | 10 |
| How to report data using the online form..... | 11 |
| Table 1: Report the number of patients receiving their 1st allogeneic and/or 1st autologous transplant and/or their 1st CAR-T/Gene therapy in 2024: | 11 |
| Table 2: Number of patients receiving Non-HSCT Cellular Therapies using manipulated or selected cells (excluding DLI and CAR-T) in 2024: (CAR-T patients are now reported in Table 1)..... | 12 |
| Table 3: Number of patients with unmanipulated DLI infusions in 2024:..... | 13 |
| Table 4: Number of patients receiving Immunosuppressive Treatments (IST) for acquired Bone Marrow Failure Syndromes in 2024:..... | 13 |



Introduction

Welcome to the EBMT Transplant Activity Survey for 2024! The Transplant Activity Survey serves as a valuable tool for assessing the real picture of HCT in Europe. This survey delivers a dual purpose: offering insights into current trends and providing essential data for counselling, planning, and decision-making.

The dedicated participation of teams allow us to track changes over time and identify factors influencing the field. This survey is invaluable for individual transplant teams, national organizations, healthcare agencies, the industry, and patients whose lives are impacted by these therapies.

Last year, we successfully transitioned from a traditional document format to a digital, online survey using Jotform, and in the first year alone, 88.5% of submissions came through this platform—a significant milestone.

Now in its second year, with centres more familiar with the online system, we have introduced some updates to the survey's content. These changes are essential to ensure the survey evolves to accurately capture the full picture of hematopoietic stem cell transplantation across Europe, especially as new treatments become increasingly common. Despite these adjustments, insights and comparisons from previous years remain relevant and valuable. We encourage all transplant teams to continue contributing to this important initiative.

How to access, use and submit the online form

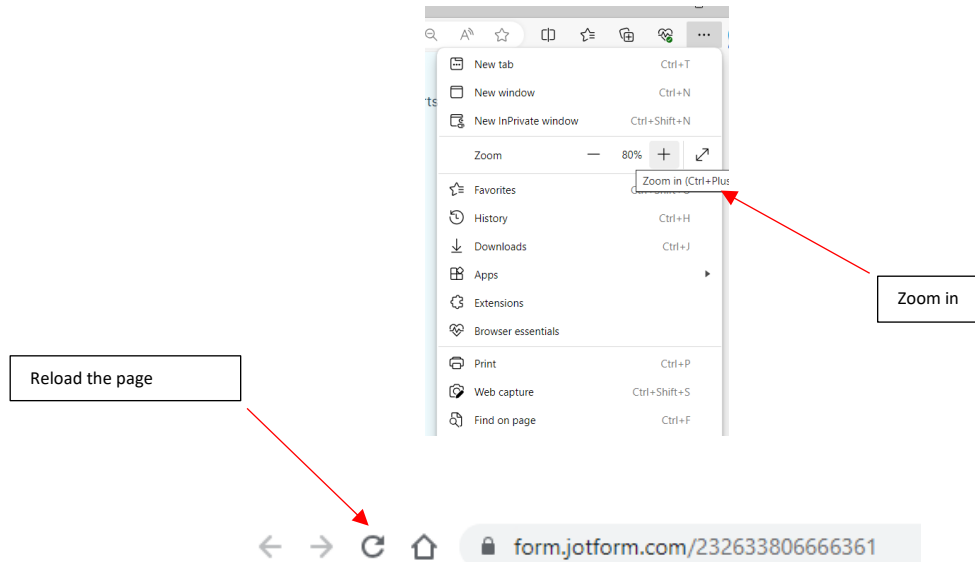
Access and features of the online survey

The EBMT has provided you with a [link](#) which takes you to the digital platform where the online survey is hosted. By clicking the link you are directed to the online survey and you can start filling in the requested information. Note that the online survey can only be filled on a computer and is not suitable to be filled on a smartphone or tablet. Also, the online survey is suitable for Chrome and Edge browsers, therefore if you are using any other browser, please, switch to one of these aforementioned browsers. **Before you start filling in your data, we advise you to read these guidelines.**

User-friendly features

The digital format of this survey offers several user-friendly features to the participants, including the ability to scroll through the form, zoom in or out, and easily navigate through its various sections. The survey includes various types of input fields, such as checkboxes, text fields, and dropdown menus. In the case of checkboxes, simply "check" the box if the statement applies to your centre.

Once you click on the survey link, it is possible that the full names of various diagnosed will not be displayed properly. To fix this, you can **zoom in**. Then, you must **reload the page** to be able to see the names correctly.



Error messages

The online survey is designed to provide error messages when a participant makes a mistake, helping them correct their input before submission. For instance if you press "Submit" too soon, an error message will appear if any required fields left empty. However, if all required fields are filled then by pressing "Enter", the form will be submitted.

The picture below shows the **11 mandatory fields** that need to be checked/filled out **before** the submission of the online survey. Mandatory fields can be recognised by the red asterisk (*) that they have at the right end of the statement/question.

Some of those fields, will trigger some parts of the form, depending on your answers. This is to avoid having data entry errors and wrong information reported.

Has the Team changed for this centre, compared to what is written above? (When it is correct, then continue) *

Our Team is the same for this centre

Our Team has changed for this centre

This field is required.

Name of person filling out this form *

This field is required.

Does this centre perform HSCT/Cellular therapies on paediatric patients, adults, or both? *

Adults

Paediatric

Both - Adults and Paediatrics

This field is required.

I have read the [Activity Survey manual](#) *

This field is required.



Does this centre perform non HSCT cellular therapies using manipulated or selected cell? *

- Yes
- No

This field is required.

Does this centre perform unmanipulated DLI infusions in 2024? *

- Yes
- No

This field is required.

Does this centre perform Immunosuppressive Treatments (IST) for acquired Bone Marrow Failure Syndromes in 2024? *

- Yes
- No

This field is required.

Representative's full name (to be displayed in Appendix) *

This is the full name of the representative from your centre that you would like to be displayed in the Appendix of the Activity Survey Publication.

This field is required.

Email for receiving a copy of the form *

example@example.com

This field is required.

Finished the survey? *

Are you finished completing the survey? The next page is Review, on which there is the Submit button.

This field is required.

Data Protection *

By submitting my responses to this survey form, I confirm my wish to have my data saved in the EBMT Transplant Activity Survey. My personal data will be used only for the purposes of maintenance of this service which includes communications and updates regarding the EBMT Transplant Activity Survey. The personal data provided will be processed according to the General Data Protection Regulation (GDPR 2016/679) and stored in an electronic database located in the EEA (European Economic Area) or in countries that are provided with the same level of protection for privacy. Data Subjects have the right of access, rectification of his/her personal data and to withdraw consent. If, as a Data Subject, you wish to exercise any of the rights listed above, please write to data.protection@ebmt.org. For further information please go to the Privacy Policy on www.ebmt.org/privacy-policy

This field is required.

Submission Guidelines

Before submission, please check the two mandatory fields that are located at the end of the form. This is necessary to successfully submit your response. Please note that only one submission is allowed per centre; multiple submissions from the same centre are not permitted. In case of a data entry error or a non-intentional submission, please contact us via email at activitysurvey@ebmt.org.

Finished the survey? *

Are you finished completing the survey? The next page is Review, on which there is the Submit button.

This field is required.

Data Protection *

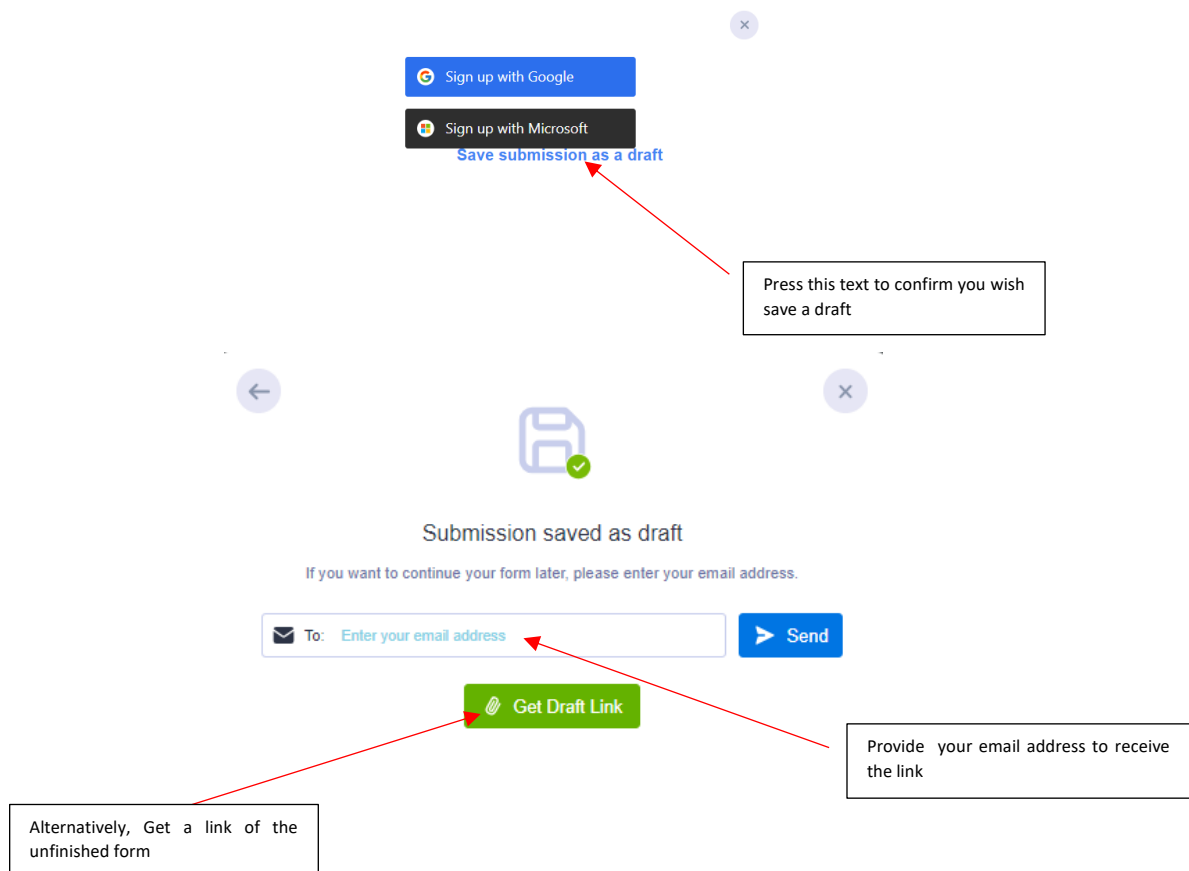
By submitting my responses to this survey form, I confirm my wish to have my data saved in the EBMT Transplant Activity Survey. My personal data will be used only for the purposes of maintenance of this service which includes communications and updates regarding the EBMT Transplant Activity Survey. The personal data provided will be processed according to the General Data Protection Regulation (GDPR 2016/679) and stored in an electronic database located in the EEA (European Economic Area) or in countries that are provided with the same level of protection for privacy. Data Subjects have the right of access, rectification of his/her personal data and to withdraw consent. If, as a Data Subject, you wish to exercise any of the rights listed above, please write to data.protection@ebmt.org. For further information please go to the Privacy Policy on www.ebmt.org/privacy-policy

This field is required.



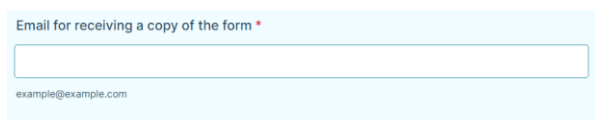
Saving Progress

The online survey also offers the option to save your progress if you don't wish to complete the survey in one session. To do this, click the "Save" button at the end of the form. A window will then appear, asking you to either log in or sign up by creating an account. **It's important to note that logging in or creating an account with Jotform is not mandatory.** You can simply click "Save a submission as draft" and provide your email address. This will allow you to receive a link to the unfinished form. Alternatively, you can select "Get Draft Link." Save this link on your computer, and you can return to it later to complete the survey.



Receive a copy of the submission

Once you complete the survey and submit it through the online platform you will receive a mail (a few minutes later) at the email address you provided at the field showing in the picture.



You will see a mail confirmation with title "We have received your response for EBMT SURVEY ON TRANSPLANT AND CELLULAR THERAPY ACTIVITY 2024". In this mail you will get a copy of you submission completed. To better view the mail please scroll down to mail and click here:



[Message clipped] [View entire message](#)

In the same mail, there will be a **PDF attachment** like in the picture below:

One attachment • Scanned by Gmail ⓘ



This PDF can be downloaded, saved and printed by the centre. It has all the data entered by the centre in the online form along with some key information about the centre and the person that filled out the form. This is a new feature that EBMT had developed this year.

When a centre performs an edit on the form, the same mail will be delivered with the PDF having the most up-to-date numbers.

Centre address and team's information

The first section of the online survey has been pre-filled by EBMT and it contains information about the participant's centre. These are the current and most up to date centre address and team's information that EBMT has.

The picture below shows an example of this section with pre-filled dummy data. In case the information about your centre is out of date and needs to be updated, please contact us via email at activitysurvey@ebmt.org. Also, if your centre has recently become an EBMT member or if it is no longer an EBMT member, please contact us at activitysurvey@ebmt.org.

In case that the team of your centre has changes, please check the box "Our Team has changed for this centre". Then in the white field, please provide the names of the people who are currently in the team (including any names that existed in the team previously).



If your centre is not in the EBMT registry it should say "Not in Registry" or "No Longer in Registry"

Activity Survey's Centre ID code (Identifying code for centres in Activity Survey)

EBMT CIC
The Centre's membership code in the EBMT Registry, if your centre used to be in the EBMT registry but is no more, it will say "No longer in Registry", if your centre has never been in the EBMT registry it should say "Not in Registry"

Address of centre

Centre Name

City

Country

Team:

Note: This team item is separate from the EBMT registry and membership database. It is a centre's choice who is considered the team for the Activity Survey.

Has the Team changed for this centre, compared to what is written above? (When it is correct, then continue) *

Our Team is the same for this centre
 Our Team has changed for this centre

Please write here all current Team members, including those who are also written above. *

Please write the names like: J. Smith, K. Jackson

If the pre-filled above information, relating to Centre Address, is out of date and needs to be updated; or if you have become/are no longer an EBMT member. Please let us know by emailing activitysurvey@ebmt.org

In case that the team's information has changed, please select the option "Our Team has changed for this centre" and enter the current Team members, including those who are also written above (mandatory field). If the team is the same, please select "Our team is the same for this centre"

Contact email in case of out-of-date information

In case your centre is no longer an active centre, please check the box as shown in the picture below "This centre no longer performs HSCT or Cellular Therapies". Moreover, in case your centre was closed, merged or split with another centre, please let us know by emailing activitysurvey@ebmt.org.

Are you no longer an active centre?
 This centre no longer performs HSCT or Cellular therapies

Tables

In the picture below, you can see a portion of Table 1. The names of rows and columns are highlighted in light blue. Please note that on the left side of the table, the rows are numbered, and this numbering is used in the next section to provide more in-depth details on how to report the data.



Table 1: Report the number of patients receiving their 1st allogeneic and/or 1st autologous transplant or their 1st CAR-T/Gene therapy in 2024:

Do NOT use letters in the table, this can cause the form to freeze on submission and you to lose information!

You may include the same patient twice as long as the first occurrence of each type of transplant took place in 2024. Note that the transplant procedure starts at conditioning.

If you cannot see the full indication names, please refer to the manual on how to change the zoom of your screen.

For information about the medical terms and definitions please read the manual.

| | Indication | HLA-id sibling BM | HLA-id sibling PBSC | HLA-id sibling Cord | Twin BM | Twin PBSC | Haplo and other HLA mismatched related donors BM | Haplo and other HLA mismatched related donors PBSC | Haplo and other HLA mismatched related donors Cord | Unrelated BM | Unrelated PBSC | Unrelated Cord | Auto BM | Auto PBSC | Auto Cord | Total Allo | Total Auto | Total HSCT | CAR-T Allo | CAR-T Auto | Gene therapy |
|----|--------------------------|-------------------|---------------------|---------------------|---------|-----------|--------------------------------------------------|----------------------------------------------------|----------------------------------------------------|--------------|----------------|----------------|---------|-----------|-----------|------------|------------|------------|------------|------------|--------------|
| 1 | AML 1st CR | | | | | | | | | | | | | | | 0 | 0 | 0 | | | |
| 2 | AML in CR > 1st CR | | | | | | | | | | | | | | | 0 | 0 | 0 | | | |
| 3 | AML not in CR | | | | | | | | | | | | | | | 0 | 0 | 0 | | | |
| 4 | AML therapy related | | | | | | | | | | | | | | | 0 | 0 | 0 | | | |
| 5 | AML- MDS related changes | | | | | | | | | | | | | | | 0 | 0 | 0 | | | |
| 6 | ALL 1st CR | | | | | | | | | | | | | | | 0 | 0 | 0 | | | |
| 7 | ALL non 1st CR | | | | | | | | | | | | | | | 0 | 0 | 0 | | | |
| | Indication | HLA-id sibling BM | HLA-id sibling PBSC | HLA-id sibling Cord | Twin BM | Twin PBSC | Haplo and other HLA mismatched related donors BM | Haplo and other HLA mismatched related donors PBSC | Haplo and other HLA mismatched related donors Cord | Unrelated BM | Unrelated PBSC | Unrelated Cord | Auto BM | Auto PBSC | Auto Cord | Total Allo | Total Auto | Total HSCT | CAR-T Allo | CAR-T Auto | Gene therapy |
| 8 | CML 1st cP | | | | | | | | | | | | | | | 0 | 0 | 0 | | | |
| 9 | CML non 1st cP | | | | | | | | | | | | | | | 0 | 0 | 0 | | | |
| 10 | MDS | | | | | | | | | | | | | | | 0 | 0 | 0 | | | |
| 11 | MDS/MPN | | | | | | | | | | | | | | | 0 | 0 | 0 | | | |

The white text fields should be filled by the participant using numbers only. If you have zero patients to report, you can leave the field empty. In the grey shaded areas, the sum of each row is automatically calculated. Therefore, there's no need to manually calculate the number of patients yourself.

It is possible to use 'Tab' button on your keyboard to go through the row when filling in a particular indication. However, do not use the tab when going from one line to another, this will cause the table to grow and the bottom part of the table will no longer be visible.

Queries on the survey

After we receive your submission it is possible that will contact you again to update (a part) of your response. This may occur in case we noticed some strange counts in your submission or in case we noticed some inconsistencies with the previous year's submissions. In any case, a link will be send to you along with some indication on what to correct.

Data protection

By submitting your response as a participant to this survey form, you confirm your wish to have your data saved in the EBMT Transplant Activity Survey. The participant's personal data will be used only for the purposes of maintenance of this service which includes communications and updates regarding the EBMT Transplant Activity Survey.

The personal data provided will be processed according to the General Data Protection Regulation (GDPR 2016/679) and stored in an electronic database located in the EEA (European Economic Area) or in countries that are provided with the same level of protection for privacy.

Data Subjects have the right of access, rectification of his/her personal data and to withdraw consent. If, as a Data Subject, you wish to exercise any of the rights listed above, please write to data.protection@ebmt.org. For further information please go to the Privacy Policy on www.ebmt.org/privacy-policy



Questions and technical support

In our website <https://www.ebmt.org/registry/ebmt-transplant-activity-survey>, you can find the most important information about the Transplant Activity Survey as well as past publications.

In case of any questions or technical issues regarding the online survey, please contact us via email at activitysurvey@ebmt.org. To be able to assist you faster, you can save the link of your unfinished form and forward it to us via email along with your question.

Other ways to participate in the survey

In the unfortunate case that you are unable to fill the online survey for a reason, we would appreciate it if you could submit your centre's activity using the excel or pdf version that we have in our website <https://www.ebmt.org/registry/ebmt-transplant-activity-survey>. To do so, please follow the next steps:

1. Download the EBMT Transplant activity survey 2024 PDF form that exist in the website.
2. Complete the relevant data fields.
3. Name and save your file with your CIC number and or centre details. If you do not have a CIC number, name the file after the name of you institution.
4. Email the form activitysurvey@ebmt.org or return by post to:

EBMT Activity Survey Team

Rijnsburgerweg 10

2333 AA Leiden, The Netherlands

Participate in Satisfaction Survey

Approximately 7-14 days after the submission of your form, you will receive a mail from Jotform with title "Participate in Satisfaction Survey - EBMT Transplant Activity Survey 2024". With this mail we invite you to participate in the Satisfaction Survey. The Satisfaction Survey was launched to assess the experience of the participants with the online platform and to collect feedback regarding the medical content of the survey. It is crucial that you participate in this short survey to help us improve the EBMT Transplant Activity Survey.

The link to the online survey will be available in the mail. To access the survey click here:

To participate in the survey, please click [here](#).



Link to the Satisfaction Survey



How to report data using the online form

Table 1: Report the number of patients receiving their 1st allogeneic and/or 1st autologous transplant and/or their 1st CAR-T/Gene therapy in 2024:

Report the 1st allogeneic transplant and/or 1st autologous transplant per patient according to disease indication, donor type and stem cell source as outlined in Table 1. You may include the same patient twice as long as the first occurrence of each type of transplant took place in 2024. Patients without consent to share data should also be reported to the survey.

Report the number of patients receiving their 1st CAR-T allo, 1st CAR-T auto or their 1st Gene Therapy in 2024 by indication using the 3 columns at the right end of Table 1. Report both patients with or without transplants. Patients in clinical trials may also be reported.

Note: The transplant procedure starts at conditioning. If a patient dies immediately after being given the cell infusion or during conditioning and before being given the cell infusion, the patient is still within the transplant procedure and must be reported.

The following EBMT/JACIE/FACT definitions for '1st transplants' apply:

- first transplant (new patient, never transplanted before)
- first allograft (after a previous autograft) or first autograft (after a previous allograft)
- first allograft or first autograft in your centre after a previous transplant in a different centre.

CAR T cells: T cells that are genetically modified by viral or non-viral vector to express chimeric antigen receptors or T cell receptors

Gene therapy: genetic modification of autologous HSCs of hematopoietic cells for therapeutic purposes

Disease classification: the classification of diseases for the survey follows the WHO classification of tumours of hematopoietic and lymphoid tissues and the EBMT disease classification dictionary, which can be found at <https://www.ebmt.org/registry/ebmt-data-collection>

The following definitions for donor type apply:

HLA-id sibling: HLA identical sibling.

Haplo (≥ 2 loci mismatch): any family member with 2 or more loci mismatch within the loci HLA-A, -B, -C, -DRB1 and -DQB1 in GvH and/or HvG direction.

Other HLA mismatched related donors: any other HLA mismatched related donor who is not included in the definition above.

For combinations of stem cell products report as follows:

- bone marrow and peripheral blood = peripheral blood stem cell transplant - enter as PBSC
- bone marrow and cord blood = cord blood transplant - enter as Cord
- peripheral blood and cord blood = cord blood transplant - enter as Cord
- bone marrow and peripheral blood + cord blood = cord blood transplant - enter as Cord



Row 39: Total number of patients receiving their 1st: allograft/autograft/CAR-T/Gene Therapy in 2024 (= total of rows 1-38).

Row 40: Total number of additional or retransplants (non 1st HSCT) due to graft failure, relapse, other events or those that are part of planned multiple transplant protocols. Total number of additional (non 1st CAR-T/Gene Therapy) due to any reason given in 2024. Report only those that were given in 2024.

Row 41: Total of all transplants and CAR-T/Gene Therapies performed in 2024 as reported in rows 1-38 + row 40.

Row 42 : Number of paediatric patients (age <18 at HSCT) receiving their 1st allograft or 1st autograft or their 1st CAR-T/Gene therapy in 2024. Report twice: in rows 1-38 individually and as a total number in row 42.

Additional information

- Allogeneic cells given after a previous allogeneic HSCT for relapse or evidence of graft rejection or when there is conditioning (chemo and/or TBI), regardless of donor type or stem cell source, is considered to be a retransplant, report in row 40.
- Pre-planned double or triple allogeneic or autologous transplants, each preceded by its own conditioning regimen are considered to be additional transplants, report in row 40.
- Reinfusion of allogeneic peripheral blood progenitor cells from the same donor without conditioning, with no evidence of graft failure is considered to be an 'allo boost' and not a transplant, report under graft enhancement – other therapies in Table 2 row 2.
- Reinfusion of autologous peripheral blood progenitor cells as a rescue for a failed graft is an auto 'boost' or 'top up' and is not considered to be a transplant, report under graft enhancement – other therapies in Table 2 row 2.
- Multiple infusions of the same product, e.g. double cord, multiple cord, multiple PBSC, given within one week are considered to be one transplant only.
- Autologous stem cells given together with an allogeneic transplant within 7 days are considered to be one allogeneic transplant.
- Syngeneic twin transplants, with either BM or PBSC can be reported together in one column.

Table 2: Number of patients receiving Non-HSCT Cellular Therapies using manipulated or selected cells (excluding DLI and CAR-T) in 2024: (CAR-T patients are now reported in Table 1)

Report the number of patients receiving NON-HSCT cellular therapies in your centre in 2024 by indication and cell type for which the therapy is given. Report both patients with or without transplants. Patients in clinical trials may also be reported.

Note: CD34+ selected transplants or for example CD3+ /CD19+ deleted cell infusions are to be reported as transplants in Table 1.



Selected/expanded T cells or Cytokine Induced Killer cells (CIK): non genetically modified T cells selected, expanded in vitro or cytokine activated. This includes all manipulated T cell infusions, with either positive or negative selection.

Regulatory T cells (TREGS): T cells that are processed after harvesting by selecting for the subset of regulatory T cells.

Other genetically modified T cells: other genetically modified T cells with suicide genes or other genes.

NK cells: cells that are processed after harvesting by selecting for NK cells with or without expansion or genetic modification.

Dendritic cells: antigen presenting cells that are used for tumour cell vaccination and other purposes.

MSC: mesenchymal stromal cells.

Expanded CD34+ cells: stem cell products that are expanded in vitro prior to infusion to the patient.

Genetically modified CD34+ cells: genetically modified stem cells, typically used for congenital diseases.

Other therapies: allogeneic or autologous boosts and any other cellular therapies not listed above.

Table 3: Number of patients with unmanipulated DLI infusions in 2024:

Number of patients receiving their 1st donor lymphocyte infusion (DLI) in 2024 in your centre (this may or may not be the site of production) or the number of patients receiving a new DLI episode. Report the main reason, if more than one exists, for giving the DLI at the time of infusion.

The year the transplant was done does not affect the DLI reporting itself. If the breakdown of DLI is unknown, please give the total number of patients receiving DLI. Any manipulated T cell infusions with either positive or negative selection should be reported as a cell therapy in table 2 above.

Table 4: Number of patients receiving Immunosuppressive Treatments (IST) for acquired Bone Marrow Failure Syndromes in 2024:

Report the number of patients receiving Immunosuppressive Treatments (IST) for acquired Bone Marrow Failure Syndromes in 2024 in your centre. Report the number of patients treated with IST for Aplastic Anaemia (AA) and for other Bone Marrow Failure Syndromes separately.

Note: If your centre is not able to provide the number of IST patients with a breakdown by Aplastic Anaemia and Other Bone Marrow Failure Syndromes, please provide the total number of IST.