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Introduction

Welcome to the EBMT Transplant Activity Survey for 2023! The Transplant Activity Survey serves as a valuable tool for assessing the real picture of HSCT 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.

Starting this year, we are excited to announce a significant improvement in the Transplant Activity Survey. We have transitioned from the traditional document format to a digital, online survey created with Jotform. This digital transformation was driven by our commitment to enhance the efficiency and effectiveness of data collection while keeping the content consistent with previous years.

Despite this digital shift, the core content, including the survey tables, medical terminology and definitions, remains unchanged. Participants can expect the same familiar and valuable content they have been accustomed to in previous years, ensuring continuity and consistency in data collection and analysis. This ensures that the insights and comparisons from the past years are still relevant and meaningful. We invite all transplant teams to be a part of this essential endeavour.

How to access, use and submit the online form

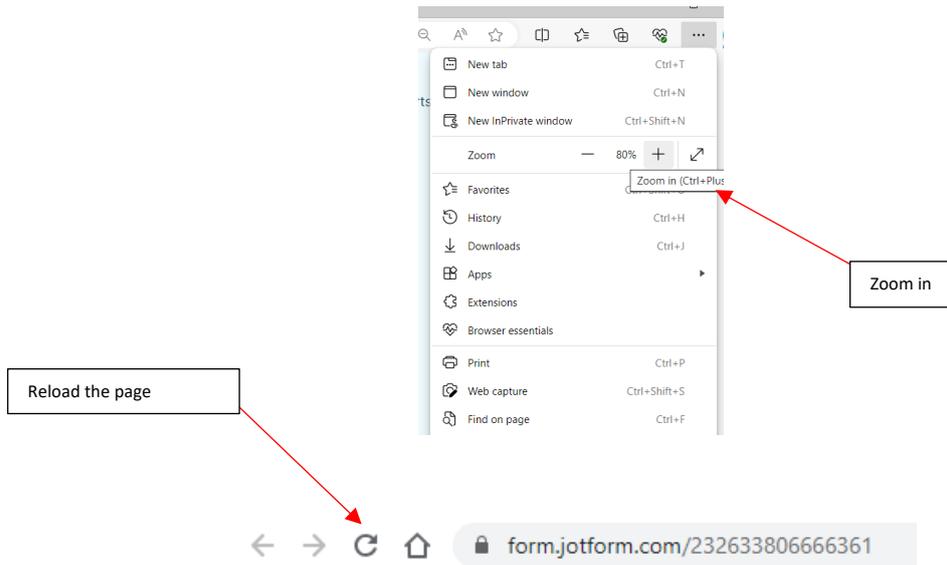
Access and features of the online survey

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.

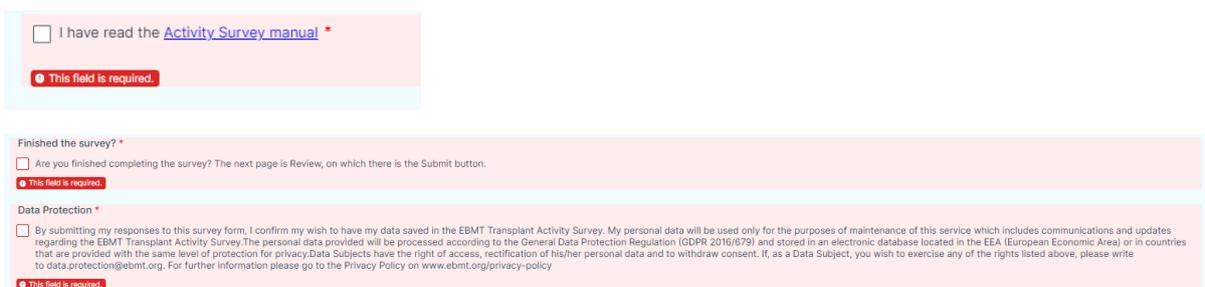
Once you click on the survey link, it is possible that the full names of various diagnosed will not be displayed properly. To fix this, you can **zoom in**. Then, you must **reload the page** to be able to see the names correctly.



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 3 mandatory fields that need to be checked **before** the submission of the online survey. These mandatory fields were added to prevent the participants to accidentally submit their form before completion. Therefore, we advise you to check these boxes when you are done with the online survey.



The image shows three mandatory fields in a survey form, each with a red error message: "This field is required." The fields are:

- I have read the [Activity Survey manual](#) *
- Finished the survey? *
 Are you finished completing the survey? The next page is Review, on which there is the Submit button.
- 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.

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.

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 "Skip Create an Account" and provide your email address. This will allow you to receive a link to the unfinished form.



Alternatively, you can click "Skip Create an Account" and then select "Get Draft Link." Save this link on your computer, and you can return to it later to complete the survey.

The screenshot shows a user interface for saving a submission as a draft. At the top, there is a blue button labeled "Save submission as a draft". Below it, a message reads "Submission saved as draft" with a floppy disk icon and a green checkmark. A sub-message says "If you want to continue your form later, please enter your email address." Below this is an email input field with the placeholder text "To: Enter your email address" and a blue "Send" button. A green button labeled "Get Draft Link" is positioned below the email field. Three callout boxes with red arrows point to these elements: one points to the "Save submission as a draft" button with the text "Press this text to confirm you wish save a draft"; another points to the "Get Draft Link" button with the text "Alternatively, Get a link of the unfinished form"; and a third points to the email input field with the text "Provide your email address to receive the link".

Receive a copy of the submission

There are two ways in which a participant can receive a copy of its submission:

1. Download or print the form:

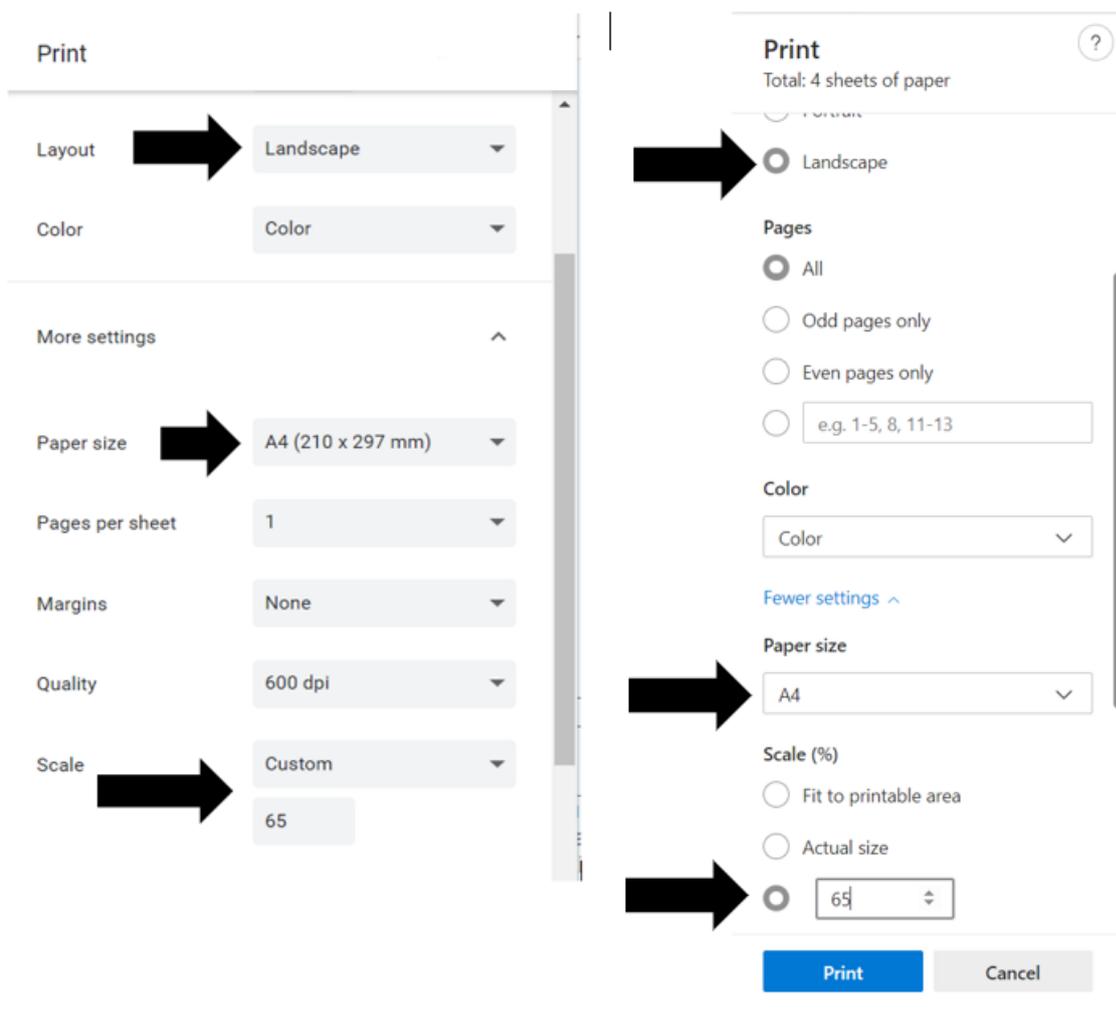
There is an option to download the form. To do so press "Review Answers" and then scroll down in the preview of the form and press "Print".

The screenshot shows the bottom of a survey form. It includes a question "Finished the survey?*" with a sub-question "Are you finished completing the survey? The next page is Review, on which there is the Submit button." Below this is a "Data Protection*" section with a paragraph of text. At the bottom, there are three blue buttons: "Back to Form", "Print", and "Submit". A red arrow points from the "Print" button to a callout box.

Press print to be able to proceed



Then a new window will come up where you can print the form or you can save it as pdf by clicking in the destination drop-down menu and choose "Save as PDF". We recommend saving it as **landscape, in custom scale of 65, A3 or A4**. Then press save or print.



These examples are from Chrome (left) and Microsoft Edge (right)



2. Receive copy by email

If you want to receive a copy of your submission you must fill in your email address in the white field that is shown in the picture below.

Email for receiving a copy of the form

example@example.com

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).

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:

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

Our Team has changed for this centre

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

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

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

In case that the team's information has changed, please check the box "Our Team has changed for this centre" and enter the current Team members, including those who are also written above.

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

The tables in the online survey have remained the same as those used in past surveys. However, they now have new functionality that allows for some additional features. In the picture below, you can see a portion of Table 1 filled with dummy data. 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.

	Indication	HLA- id BM	HLA- id PBSC	HLA- id Cord	Twin BM	Twin PBSC	Haplo (≥ 2 loci mismatch) BM	Haplo (≥ 2 loci mismatch) PBSC	Other Family Member BM	Other Family Member PBSC	Other Family Member Cord	Unrelated BM	Unrelated PBSC	Unrelated Cord	Auto BM	Auto PBSC	Auto Cord	Total Allo	Total Auto	Total HSCT	No. allo after auto
1	AML 1st CR	1	2	1														4	0	4	
2	AML non 1st CR																	0	0	0	
3	AML: therapy related	1	1	2														4	0	4	
4	AML: MDS related changes																	0	0	0	
5	ALL 1st CR		1				1											2	0	2	
6	ALL non 1st CR																	0	0	0	
	Indication	HLA- id BM	HLA- id PBSC	HLA- id Cord	Twin BM	Twin PBSC	Haplo (≥ 2 loci mismatch) BM	Haplo (≥ 2 loci mismatch) PBSC	Other Family Member BM	Other Family Member PBSC	Other Family Member Cord	Unrelated BM	Unrelated PBSC	Unrelated Cord	Auto BM	Auto PBSC	Auto Cord	Total Allo	Total Auto	Total HSCT	No. allo after auto
7	CML 1st cP	1				1												2	0	2	
8	CML non 1st cP		1															1	0	1	

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

If you prefer not to have your name shared with us or if you/the representative prefers not to have their name in stored by us then you may leave the 'Name of person filling out this form' and 'Representative's full name' field empty. Note if the 'Representative's full name' is empty it will not be published in the upcoming publication appendix. You or any team member may also request to have their name removed from the Team field, to do this contact us as activitysurvey@ebmt.org.

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 2023 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



How to report data using the online form

Table 1: Report the number of patients receiving their 1st allogeneic and/or 1st autologous transplant in 2023:

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 2023. Patients without consent to share data should also be reported to the survey.

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.

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 family member: any other family member who is not included in the definitions 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 33: Total number of patients receiving their 1st allograft or 1st autograft in 2023 (= total of rows 1-32).

Row 34: 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. Report only those that were given in 2023.

Row 35: Total of all transplants performed in 2023 as reported in rows 1-32 + row 34.

Row 36: Number of paediatric patients (age <18 at HSCT) receiving their 1st allograft or 1st autograft in 2023. Report twice: in rows 1-32 individually and as a total number in row 36.

Row 37: Number of allogeneic transplants with non-myeloablative conditioning (including Reduced Intensity Conditioning (RIC)) as reported in row 35.



Row 38: Number of patients receiving their 1st donor lymphocyte infusion (DLI) in 2023 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 check the box “The breakdown of DLI unknown” and 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 – see below.

Row 39: Number of patients receiving Immunosuppressive Treatments (IST) for Bone Marrow Failure Syndromes (acquired and congenital) in 2023 in your centre. Report the number of patients treated with IST for Aplastic Anaemia (AA) and for other Bone Marrow Failure Syndromes separately.

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 34.
- 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 34.
- 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.

No. allo after auto: refers to the number of patients who receive their 1st allograft in 2023 after a previous autograft (the year when the previous autologous HSCT was performed does not matter). Enter both the 1st allograft and 1st autograft (only if also performed in 2023) in Table 1 by indication and donor type and additionally as a total number in the column ‘No. allo after auto’ on the right-hand side. If an allogeneic HCT for a different indication is given after an autologous HCT, it should not be counted as an ‘allo after auto’.

Table 2: Number of patients with non HSCT cellular therapies

Report the number of patients receiving NON-HSCT cellular therapies in your centre in 2023 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.



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

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.