2804: CIBMTR Research ID Assignment

The CIBMTR Research ID (CRID) is a unique identifier assigned when an individual is registered with CIBMTR as receiving a cellular therapy, including hematopoietic stem cell transplant (HCT), cellular therapy (CT), treatment for marrow toxic injuries, or certain non-cellular therapies. The CRID Assignment Tool 2804 collects the information required to create a lifelong identification number specific to an individual, and certain data fields are used to ensure that the same individual does not inadvertently receive multiple CRID assignments.



Reporting of all HCTs is important to ensure the continued epidemiological integrity of the CIBMTR outcomes registry. The exception to this is if your center performs but does not report autologous HCTs.

By creating a unique identifier and ensuring participants receive only a single CRID, CIBMTR is better able to carry out its charge as a co-contractor of the C.W. Bill Young Transplantation Program with the responsibility for maintaining the Stem Cell Therapeutic Outcomes Database (SCTOD). The CRID is used to ensure the accuracy of center-specific outcomes by adjusting survival expectation for patients receiving multiple HCTs and allowing for verification of survival status within the National Death Index. Additionally, the CRID can be used to help re-establish contact with individuals who are lost to follow-up and to ensure that all allogeneic HCT recipients in the US, or receive a product from the US, are reported to CIBMTR.

Completeness of the Form 2804 is important for ensuring that individuals are not assigned multiple CRIDs over their lifetime. The system is able to assign an identification number when some identifying fields are missing, but this increases the risk of duplicate reporting. Therefore, the following guidelines have been established:

- For all individuals, complete the form as thoroughly as possible
- · In the event of a state law or IRB policy that supersedes federal statute, centers may opt out of providing some of these data

CIBMTR carefully ensures that identifying information is collected and stored in a secure manner. The electronic systems that generate CRIDs have undergone rigorous certification and authorization from HRSA's Office of Information Technology and they comply with all US regulations relevant to security of data in federal databases.

Once the identifying data are entered into FormsNet3 and a CRID is assigned, the identifying data are held within the CIBMTR Research ID Assignment (2804) Form and are not visible in any other locations in FormsNet3. For that reason, it is important that the information is accurate when submitted. The identifying information used to create the CRID will not appear on any subsequent forms or correspondence.

Transplant centers need to take appropriate measures at their site to secure the identifying information used to generate the CRID.



This form only needs to be completed for patients who have not previously been assigned a CRID. If a duplicate CRID is inadvertently created or identified, contact CIBMTR Center Support to resolve.

Q1-13: Demographics

Q14-18: Recipient Identifiers

Q19-22: Outcomes Registry Reporting

Manual Updates:

The most recent updates to the manual can be found below. If you need to reference the historical version for this form, see the retired manual section on the Retired Forms Manuals webpage.

Date	Manual Section	Add/ Remove/ Modify	Description
3/9/ 2021	2804: CIBMTR Research ID Assignment Form	Add	Added the following instructions to question 10: Indicate the detailed race of the recipient. If this recipient has reported that they are more than one detailed race, check each detailed race indicated in the list below that applies. If the race detail is not documented or is not known, select "unknown."
3/9/ 2021	2804: CIBMTR Research ID Assignment Form	race. If this recipient has reported that they are more than one race race indicated in the list below that applies. The race groups provide specific to the United States. If the recipient is White, Southeast As Pacific Islander, but a more specific Race Detail is not available, re-	

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Q1-13: Demographics



This form must be completed for all individuals whose data is submitted to CIBMTR. CIBMTR is a Public Health Authority (PHA) under the Health Insurance Portability and Accountability Act (HIPAA). In this capacity, CIBMTR is authorized to collect individually identifiable health information without consent or authorization of the individual. The PHA designation also allows transplant centers, which fit the definition of covered entities, to disclose these data to CIBMTR under 45 CFR 164.512 (Privacy Rule) without direct consent or authorization of the recipient.

Complete all data fields as thoroughly as possible.

Questions 1-2: First Name, Last Name

Report the individual's complete legal first name in question 1 and complete legal last name in question 2. If you are unable to report the full legal name, reporting initials or partial name can be reported and help to reduce duplicate CRIDs.

Question 3: Date of birth

Reporting the individual's date of birth is required for all Form 2804 submissions. Report the individual's date of birth and continue with question 4.

Questions 4-6: Location of birth

Report the individual's country of birth in question 4. If applicable, specify city and state of birth in questions 5-6, respectively.

Question 7: Sex

Reporting the individual's sex is required for all Form 2804 submissions. Report the individual's biological sex and continue with question 8.

Question 8: Ethnicity

Indicate the recipient's ethnicity. The United States Office of Management and Budget (OMB) has defined ethnicity as culturally or geographically determined. The distinction between Hispanic and non-Hispanic is for the purpose of the United States census and reporting of SCTOD data. According to OMB, "Hispanic" is an ethnic designation based upon where someone (his or her ancestors) was raised (e.g., "Latin America"). Hispanic people may be of any race. CIBMTR recognizes regional differences with regard to the interpretation of ethnicity throughout the world.

If the recipient is not a resident of the US, select "not applicable."

If the recipient declines to provide this information or the recipient's ethnicity is not documented, select

"unknown."

For more information regarding ethnicity, see Appendix I.

Question 9: Race (check all that apply)

Indicate the recipient's race. If this recipient has reported that they are more than one race, check each race indicated in the list below that applies. The race groups provided are specific to the United States.

For non-US centers, select "not reported" if the rules / regulations of your country prohibit the collection or reporting of race data (or due to lack of documentation). If race is reported, it may be necessary to consult with the recipient to select the race group(s) with which they most closely identify.

If the recipient declines to provide this information, select "not reported."

If the recipient's race is not documented, select "unknown."

For more information regarding race, see Appendix I.

Question 10: Race detail (check all that apply)

Indicate the detailed race of the recipient. If this recipient has reported that they are more than one detailed race, check each detailed race indicated in the list below that applies.

If the race detail is not documented or is not known, select "unknown."

For more information regarding race, see Appendix I.

Question 11: Social security number

Report the individual's social security number. If the individual's social security number is unknown or the individual is not a US citizen, leave this data field blank.

Question 12: Cadastro de Pessoas Físicas (CPF) (Brazilian citizens only)

If the individual is a citizen of Brazil, report their 11-digit Cadastro de Pessoas Físicas (CPF). If the individual's CPF is unknown or the individual is not a Brazilian citizen, leave this data field blank.

Question 13: Patient's mother's maiden name (optional for non-US centers)

Report the individual's mother's maiden name. This field may be left blank if the individual's mother's maiden name is unknown, the HCT recipient declined to release mother's maiden name, or your transplant center is located outside the US.

Section Updates:

Question Number	Date of Change	Add/ Remove/ Modify	Description	Reasoning (If applicable)
Q9	3/9/ 2021	Remove	The following instructions were removed: _Indicate the recipient's race. If this recipient has reported that they are more than one race, check each race indicated in the list below that applies. The race groups provided are specific to the United States. If the recipient is White, Southeast Asian, or Pacific Islander, but a more specific Race Detail is not available, report the patient is "Other [White, Southeast Asian, or Pacific Islander respectively].	Removed incorrect instructions
Q10	3/9/ 2021	Add	The following instructions were added: Indicate the detailed race of the recipient. If this recipient has reported that they are more than one detailed race, check each detailed race indicated in the list below that applies. If the race detail is not documented or is not known, select "unknown."	Added for clarification

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Q14-18: Recipient Identifiers

Complete all additional individual identifiers, as applicable.

Question 14: Recipient NMDP ID

Report the seven-digit recipient ID (RID) assigned by NMDP. If the individual has never been assigned an NMDP RID, leave this data field blank. For <u>RELATED</u> donors, do not report the repository sample ID in this field. For <u>UNRELATED</u> donors, the RID is the sample ID.



If an NMDP RID is assigned after the initial submission of the CRID Assignment (2804) Form or it was missed at initial entry, please edit the CRID Assignment page to add this data.

Question 15: Recipient IUBMID

Report the six-digit IUBMID previously assigned to the individual. The IUBMID is the individual identifier previously assigned by the International Bone Marrow Transplant Registry (IBMTR), which was the precursor to the current CRID system. If an IUBMID was previously assigned, complete and continue with question 16; if no IUBMID was previously assigned, continue with question 17.

Question 16: Team ID

Report the four-digit team ID; this data field is required if question 15 is answered. The Team ID is a precursor to the current CIBMTR center number (CCN) system, used by the IBMTR. If the individual has a previously assigned IUBMID, there should be an associated Team ID.

Question 17: Institution-specific subject ID

Report the subject identifier used for any center-specific outcomes registration, transplant study protocol(s), or other unique subject identifier used for internal institutional tracking. <u>Do not</u> report the recipient medical record number (MRN). If the individual does not have an institution-specific subject ID, leave this data field blank.

Question 18: Transplant Registry Unified Management Program (TRUMP ID) (Japanese centers only)

If the individual is a citizen of Japan, report their 12-digit Transplant Registry Unified Management Program (TRUMP ID). If the individual's TRUMP ID is unknown or the individual is not a Japanese citizen, leave this data field blank.

Section Updates:

Question Number	Date of Change	Add/Remove/Modify	Description	Reasoning (If applicable)
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Q19-22: Outcomes Registry Reporting

Indicate and provide identifiers for all other outcomes registries the individual's data are being reported to. If the individual's data are not being reported to any other outcomes registries, continue with the signature section of the form. If the individual's data are being reported to multiple additional outcomes registries, create a new instance for each additional outcomes registry.

Question 19: Specify outcomes registry

Indicate all outcomes registries the individual's data are being reported to; if the individual is participating in more than one registry, add a new instance for each. As a reference, the registry acronyms and instructions for proceeding with the remainder of the form are detailed below:

- EBMT: European Society for Blood and Marrow Transplantation, continue with question 20.
- USIDNET: United States Immunodeficiency Network, continue with question 22.
- **APBMT**: Asia-Pacific Blood and Marrow Transplantation Group, continue with question 22.
- **CBMTG**: Canadian Blood and Marrow Transplant Group, continue with the signature section of the form or create an additional instance of questions 19-22 to report additional outcomes registries.
- EMBMT: Eastern Mediterranean Blood and Marrow Transplantation Group, continue with question 22.
- The National MDS Study: The National MDS Study refers to an NHLBI-sponsored study looking at the natural history of MDS; this is not the same as 10-CMSMDS-1, the HCT for MDS Medicare Study. If the individual's data are being reported to the National MDS Study, continue with question 22.
- Other outcomes registry, continue with question 21

Question 20: EBMT CIC

For individuals with data reported to EBMT, report the four- to five-digit Centre Identification Code (CIC) identifying the transplant center. Continue with question 22 and specify the EBMT subject identifier.

Question 21: Specify other outcomes registry

Report the other outcomes registry the individual's data are being reported to. Use the complete registry name, rather than acronyms or abbreviations. Continue with question 22.

Question 22: Outcomes registry subject ID

Report the registry subject ID for the applicable registry; if multiple instances of questions 19-22 are being reported, ensure the registry subject ID corresponds with the registry indicated in the same instance of question 19.

Section Updates:

Question Number	Date of Change	Add/Remove/Modify	Description	Reasoning (If applicable)