2804: CIBMTR Research ID Assignment Form

The CIBMTR Research ID (CRID) is a unique identifier assigned when an individual is registered with the CIBMTR as receiving a cellular therapy, including hematopoietic stem cell transplant (HCT), treatment for marrow toxic injuries, and certain non-cellular therapies. The CRID Assignment Form 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, the 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 United States, or who receive a product from the United States, are reported to the 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.
  The 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 United States regulations relevant to security of data in federal databases.

Once the identifying data are entered into FormsNet and a CRID is assigned, the identifying data are no

longer visible to the transplant center or CIBMTR staff. 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 CIBMTR Research ID (CRID). If a duplicate CRID is inadvertently created or identified, please contact your CRC to resolve.

Q1-9: Demographics
Q10-13: Recipient Identifiers
Q14-17: Outcomes Registry Reporting

Manual Updates:
Sections of the Forms Instruction Manual are frequently updated. The most recent updates to the manual can be found below.

If you need to reference the historical version for this form, please find the retired manual section on the Retired Forms Manuals webpage.

Date	Manual Section	Add/ Remove/ Modify	Description
8/29/16	2804: CIBMTR Research ID Assignment form	Add	Added information banner to 2804 introduction page: 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.
5/29/15	2804: CIBMTR Research ID Assignment form	Add	Added text to question 14: • 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 17.
05/12/	2804: CIBMTR	Add	Updated manual for new 2804

2015	Research ID Assignment form		

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Q1-9: Demographics

This form must be completed for all individuals on whom 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 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

Report the individual's biological sex.

Question 8: 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 United States citizen, leave this data field blank.

Question 9: Patient's mother's maiden name (optional for non-U.S. 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 autologous HCT recipient declined to release mother's maiden name, or your

transplant center is located outside the United States.

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Q10-13: Recipient Identifiers

Complete all additional individual identifiers, as applicable.

Question 10: Recipient NMDP ID

Report the seven-digit recipient ID (RID) assigned by the National Marrow Donor Program (NMDP). If the individual has never been assigned an NMDP RID, leave this data field blank.

Question 11: 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 12; if no IUBMID was previously assigned, continue with question 13.

Question 12: Team ID

Report the four-digit team ID; this data field is required if question 11 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 13: 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. Do not report the recipient medical record number (MRN). If the individual does not have an institution-specific subject ID, leave this data field blank.

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Q14-17: 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 14: 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 15.
- USIDNET: United States Immunodeficiency Network, continue with question 17.
- APBMT: Asia-Pacific Blood and Marrow Transplantation Group, continue with question 17.
- CBMTG: Canadian Blood and Marrow Transplant Group, continue with the signature section of the form or create an additional instance of questions 14-17 to report additional outcomes registries.
- EMBMT: Eastern Mediterranean Blood and Marrow Transplantation Group, continue with question 17.
- 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 17.
- Other outcomes registry, continue with question 16

Question 15: EBMT CIC

For individual with data reported to EBMT, report the four- to five-digit Centre Identification Code (CIC) identifying the transplant center. Continue with question 17 and specify the EBMT subject identifier.

Question 16: Specify other outcomes registry

Report the other outcomes registry individual data are being reported to. Use the complete registry name, rather than acronyms or abbreviations. Continue with question 17.

Question 17: Outcomes registry subject ID

Report the registry subject ID for the applicable registry; if multiple instances of questions 14-17 are being reported, ensure the registry subject ID corresponds with the registry indicated in the same instance of question 14. Continue with the signature section of the form or create an additional instance of questions

14-17 to report additional outcomes registries.

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