

Supporting Statement A

NMDPSM Patient Support Center Survey **OMB Control No. 0906-0004-REVISION**

A. Justification

1. Circumstances Making the Collection of Information Necessary

This is a request for continued Office of Management and Budget (OMB) approval of a voluntary customer satisfaction survey titled, National Marrow Donor Program Patient Support Center Survey, under the Health Resources and Services Administration's (HRSA) generic clearance. The C.W. Bill Young Cell Transplantation Program (CWBYCTP) was established by the Stem Cell Therapeutic and Research Act of 2005 (Public Law 109 - 129) and was most recently reauthorized in 2021 (S. 288(117th): TRANSPLANT Act of 2021). The CWBYCTP Office of Patient Advocacy is operated by the National Marrow Donor Program® (NMDP). NMDP has explicit requirements to conduct surveys of patient satisfaction. As such, NMDP will elicit feedback from marrow and cord blood transplant patients, caregivers, and family members who had contact with the NMDP Patient Support Center for navigation services, educational information, and support. The survey also includes demographic questions to determine the representativeness of findings. The objectives of the survey are to 1) Determine the level of satisfaction with existing services of the Patient Support Center and 2) Determine areas for improvement and opportunities for the development of new programs and services.

This collection of information helps fulfill the requirements of Executive Order 12862, "Setting Customer Service Standards," which requires agencies that provide significant services directly to the public to identify and gather feedback from customers; establish service standards and measure performance against those standards; and benchmark customer service performance against the best customer experience provided in the private sector. Executive Order 12862 also states that "Strengthening the democratic process requires providing direct lines of feedback and mechanisms for engaging the American people in the design and improvement of Federal Government programs, processes, and services." This survey aims to gather that feedback and measure performance to improve customer experience and performance.

There are revisions to the survey since the prior approval. Some questions and phrasing on the survey have been revised for clarity, without changing the intent of the

question. Additionally, one response option has been added to the question about the respondent's education level. There are no changes to the instructions, frequency of collection, or use of the information.

2. Purpose and Use of Information Collection

Barriers restricting access to marrow and cord blood transplant-related care and educational information are multi-factorial. The CWBYCTP Office of Patient Advocacy works to help patients overcome barriers by providing access to programs, information and services related to transplant. Feedback from participants is essential to understand the changing needs for services and information as well as to demonstrate the effectiveness and satisfaction of existing services. The primary use for information gathered through the survey is to determine the helpfulness of participants' initial contact with the NMDP Patient Support Center and to identify areas for improvement in the delivery of services. Stakeholders (i.e., program managers, NMDP leadership, and HRSA) use this evaluation data make program and inform resource allocation decisions. Feedback acquired through the survey showed that the services provided by the Patient Support Center benefit patients throughout their treatment. These results have led to greater investment in patient services programs including proactive outreach to support more patients. Survey results have also led to development of additional post-transplant survivorship services

3. Use of Improved Information Technology and Burden Reduction

The NMDP Patient Support Center Survey is a web-based survey designed to reduce respondent burden (508 compliant). All responses (100%) are collected through electronic submission. This technology allows reminders to be sent only to non-responders which reduces the number of contacts during the time of decision-making and treatment.

4. Efforts to Identify Duplication and Use of Similar Information

The NMDP Patient Support Center Survey does not duplicate any other information collection tool. None of the questions are present on other evaluation instruments. The proposed survey is unique to capturing feedback that will measure the navigation program objectives and satisfaction with services.

5. Impact on Small Businesses or Other Small Entities

No small entities will be involved in this data collection.

6. Consequences of Collecting the Information Less Frequently

The survey informs program development and resource allocation but does not significantly impact program delivery as patient satisfaction has remained consistently high through each contract cycle. Giving participants the ability to provide direct feedback to the program remains important.

To reduce burden, each patient, caregiver, or family member will be administered the survey one time during a 12-month period. If the participant contacts the Patient Support Center and the survey was administered one or more years previously, the participant will receive another survey. Over time, the available resources, services, and delivery methods will have changed, and new feedback will be important for evaluating the effectiveness of the services. If the information is collected less frequently program managers will not have accurate data to effectively improve existing programs or develop new programs to meet the needs of the participant population.

7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

The request fully complies with the regulation.

8. Comments in Response to the Federal Register Notice/Outside Consultation

Section 8A:

A 60-day Federal Register Notice was published in the *Federal Register* on 1 July 2026, vol. 91, No. 125; pp. 40004-40005. There were two public comments.

The first commenter suggested that, for surveys administered repeatedly over time, previously submitted information be pre-populated to reduce respondent burden and improve the user experience. HRSA reviewed the comment and did not adopt this change because this survey is not designed to collect longitudinal data. Although pre-populated information may reduce burden in some post-transplant follow-up contexts, this survey is specific to respondents who contact the NMDP PSC immediately before and after transplant, generally within a 12-month period. Respondents generally receive the survey only once within that 12-month period after the first interaction. A subsequent survey is sent only if they had another contact with the NMDP PSC after a 12-month period. Pre-populating the survey with prior responses would not be relevant to a subsequent survey because each survey measures satisfaction with a specific interaction. The second commenter recommended administering the survey in alternate formats (such as SMS) and also suggested that survey response data should be presented in a way that clearly delineates the proportion of individuals served by the NMDP PSC who received the survey, those that did not receive the survey because no email address was provided, those that responded to the survey, and those that received the survey but did not respond. HRSA reviewed this comment and determined that suggestions related to the presentation and interpretation of survey data are consistent with existing analysis and evaluation methodologies for this survey including delineation of surveyed and non-surveyed groups within the total population. HRSA also determined that the use of SMS or other technologies for survey administration must be reviewed further for cost and implementation considerations. Therefore, no changes were made to the information collection in response to the two comments received.

A 30-day Federal Register Notice was published in the Federal Register on September 29, 2026, vol 91, No. 187, pp. 61413-15

Section 8B:

This survey was not developed with outside consultation from any agency. It was developed internally by NMDP Health Services Research staff and Patient Support Center managers.

Opportunity for public comment have been posted in the Federal Register every three years (most recently in 2020, and 2023).

9. Explanation of any Payment/Gift to Respondents

Respondents will not receive any payments or gifts.

10. Assurance of Confidentiality Provided to Respondents

This collection of information will involve names and email addresses for the purpose of administering the survey only and will fully comply with the Privacy Act. Separate databases are used for participant names and addresses and survey responses. Demographic information will be available in both databases but not used to link survey responses. A unique identifier is assigned to each participant for survey response tracking only. Given that this is not human subjects research, IRB review is not necessary.

Participation is fully voluntary, and responses are kept confidential to the extent allowed by law. Survey responses are not linked to personally identifying information, such as name and email address. Participants will be assured that their decision whether or not to participate or their responses will not have any effect on their medical care.

11. Justification for Sensitive Questions

The survey does not include sensitive questions related to sexual behavior and attitudes, alcohol or drug use, religious preferences, or other matters that are considered private. The survey does not request the respondent's social security number (SSN). The survey does ask for demographic information including race, ethnicity, gender, age group, and education level. These data are important for characterizing responses to understand if support needs and satisfaction vary by segment. Demographic questions are optional and include a "Prefer not to answer" response option. Respondents are informed that answers to these questions are confidential.

12. Estimates of Annualized Hour and Cost Burden

Respondents will include all patients, caregivers, and family members who have contact with the Patient Support Center via phone or email for bone marrow or cord blood transplant navigation services and support.

12A. Estimated Annualized Burden Hours

The annualized burden was estimated using data from the existing survey collection platform. The median response time for the survey is just over 4.5 minutes, which accounts for the time that the respondent has the survey window open on their device.

Type of Respondent	Form Name	No. of Respondents	No. Responses per Respondent	Average Burden per Response (in hours)	Total Burden Hours
Patient/ Caregiver/ Family Member	NMDP Patient Support Center Survey	1,000	1	.075	75
Total			1	.075	75

13. Estimates of other Total Annual Cost Burden to Respondents or Recordkeepers/Capital Costs

Other than their time, there is no cost to respondents.

14. Annualized Cost to Federal Government

Surveys will be administered by the NMDP PSC staff which includes effort from a Business Operations Specialist (.06 FTE, \$8,457), Market Research Analyst (.01 FTE, \$1,343) and Patient Services Managers (.04 FTE, \$8,459). Wage has been multiplied by 1.5 to account for overhead costs (e.g., benefits).

The contract task that supports this collection is for approximately \$10,313 per year.

(Based on May 2025 National Occupation and Wage Statistics

([https://data.bls.gov/oesprofile/?](https://data.bls.gov/oesprofile/?major_group=110000&occupation=119111&measure=01&areas=INDUSTRY,STATE,MSA)

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utilizing the median wage of the following comparable roles: Business Operations Specialist SOC Code 13,1000; Market Research Analyst SOC Code 13,1161; Medical and Health Services Manager SOC Code 11-9111)

15. Explanation for Program Changes or Adjustments

The estimated burden for this request is lower than the prior estimated burden. The estimated number of respondents has increased based on data from the previous three (3) fiscal years. The prior estimated average burden per response was too high. For this request, the estimated burden per response time has decreased following a review of available data of the current actual time burden experienced by respondents. There are no changes to the administration of the survey at this time in terms of the required staff time.

16. Plans for Tabulation, Publication, and Project Time Schedule

Surveys will be administered on an ongoing basis to all individuals who receive services from the Patient Support Center; there is no statistical sampling to select survey respondents. NMDP Patient Services staff will administer, collect, analyze, and report survey results to stakeholders. Ongoing data collection will utilize web-based survey software which will be entered and stored in a secure database. Responses will be analyzed using the web-based survey software. Narrative information from the surveys will be summarized and examined using descriptive analysis and/or modeling of survey data. The survey data will be analyzed quarterly and annually, and results will be shared with program managers and HRSA. Feedback indicating a need for improvement will be reviewed by program managers semiannually and implementation of resulting program changes or additions will be documented. This survey is not part of a research study. Findings will only be used for internal program improvement and will not be generalized to the public. There are no plans to publish the survey results because of the potential for respondents to include identifying information in free text boxes. Respondents are informed that their survey responses will be kept confidential. We request a 3-year clearance for this survey.

17. Reason(s) Display of OMB Expiration Date is Inappropriate

No exemption is requested. The expiration date will be displayed.

18. Exceptions to Certification for Paperwork Reduction Act Submissions

There are no exceptions to the certification.