

# Supporting Statement A

## Donation Experience Survey

### OMB Control No. 0915-0212-EXTENSION

**Terms of Clearance:** None

#### **A. Justification**

##### **1. Circumstances Making the Collection of Information Necessary**

The Health Resources and Services Administration (HRSA) currently has approval under the generic clearance, Office of Management and Budget (OMB) Control No. 0915-0212, to conduct customer satisfaction surveys and focus groups. This collection of information helps fulfill the requirements of Executive Order 12862, "Setting Customer Service Standards," which directs agencies that "provide significant services directly to the public" to "survey customers to determine the kind and quality of services they want and their level of satisfaction with existing services."

This is a request for OMB renewal of approval of a qualitative voluntary customer satisfaction survey under HRSA's 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 Single Point of Access-Coordinating Center is operated by the National Marrow Donor Program® d/b/a NMDP<sup>SM</sup> ("NMDP") which operates publicly as NMDP<sup>SM</sup>. NMDP has explicit requirements to conduct surveys on the extent of satisfaction with donor advocacy and case management services. NMDP will solicit voluntary feedback from blood stem cell donors, post-donation. A survey will be distributed electronically to donors by email within the month following their donation, with two reminders sent following the initial invite (at 7 and 15 days, respectively). The survey is available in English, Spanish, Portuguese, Korean, Chinese, and Vietnamese. The survey consists of four sections focusing on pre-donation, donation day, recovery, and overall satisfaction. The survey includes statements that use a five-point Likert-type scale ranging from "strongly disagree" to "strongly agree", multiple choice questions, and

open-ended questions which allow respondents to provide their thoughts, perceptions, and opinions.

## **2. Purpose and Use of Information Collection**

Objective(s) of data collection activities.

NMDP is seeking to better understand the overall experience and satisfaction of blood stem cell donors. The survey questions were developed to determine the donor's experience and satisfaction with their representative and care team, educational materials, access to assistance, medical care, overall satisfaction, and willingness to donate again, if requested. Survey results and feedback are monitored and reviewed to identify trends and opportunities for improvement. NMDP will assess and propose strategies to implement improvement efforts targeting donor experience, service, and process.

Donor experience and satisfaction with the care team and donation process are critical to creating strong ambassadors to encourage others to fulfill their commitment to donate bone marrow. Feedback from donors is essential to understand the changing needs for services and information as well as to gauge the helpfulness of our NMDP representatives and the educational materials and support provided. The primary use of information gathered through the survey is to determine the effectiveness of our programs and services. Additionally, NMDP is looking to identify areas for improvement in the delivery of services. Specific areas targeted in the survey gather the donor's perception regarding if NMDP helped with challenges to enable donation, if NMDP adequately addressed donor questions, if NMDP provided an accurate description of what to expect, and if NMDP assisted with additional donation support needs (i.e. securing time away from work/school, lost wage reimbursement, child care costs, etc.). NMDP also cares about the services provided by our network partners and allows donors to rate their experience, specifically with the hospital or donation facility where their blood stem cells were collected. Finally, NMDP seeks to understand if donors would be willing to donate again and/or if they would recommend donation to a friend or family member. Feedback will be reviewed monthly and reports will be available to our network partners. NMDP program managers and leadership will utilize this evaluation data to share donors' experiences as well as make program enhancements to better serve our donors.

## **3. Use of Improved Information Technology and Burden Reduction**

The web-based survey will be administered via the Qualtrics survey tool. Blood stem cell donors will be invited through email to complete the survey and the technology allows reminders to be sent only to non-responders. All responses (100%) are collected through electronic submission. The survey is voluntary as are each of the individual questions.

#### **4. Efforts to Identify Duplication and Use of Similar Information**

The survey is designed to capture data that will measure NMDP Donor Services and Donor Advocacy program objectives through overall donor satisfaction and experience. The specific questions are not present on other evaluation instruments. The survey does not duplicate any other information collection tool.

#### **5. Impact on Small Businesses or Other Small Entities**

No small businesses will be involved in this study.

#### **6. Consequences of Collecting the Information Less Frequently**

To reduce the burden, each blood stem cell donor will only be administered the Donation Experience Survey one time, unless they donate multiple times and if that is the case, they will be allowed to complete the survey after each donation (up to NMDP donation limits). The survey invitation is sent the month following their donation. There are no legal obstacles to reduce the burden.

#### **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 Federal Register Notice was published in the *Federal Register* on December 17, 2014, vol. 79, No. 242; pp. 75164. There were no public comments.

##### **Section 8B:**

We did not leverage the use of outside consultants in the development of the survey tool.

#### **9. Explanation of any Payment/Gift to Respondents**

Respondents will not receive any payments or gifts.

#### **10. Assurance of Confidentiality Provided to Respondents**

To date, the HRSA customer satisfaction surveys have not collected personally identifiable information from respondents. This collection of information will involve email addresses to administer the survey and will comply with the Privacy Act. Separate databases are used for participants' personally identifiable information and survey responses. A unique identifier is assigned to each participant for survey response tracking. Participation is voluntary and responses are kept private and confidential to the extent allowed by law. Survey comments indicating a low experience/satisfaction score are reviewed by NMDP Donor Advocacy who will work with the donor center and/or apheresis center/collection center liaisons for follow-up, as

necessary. The survey provides contact information for NMDP Donor Advocacy if desired. The Donation Experience Survey does not meet the regulatory definition of research, because the intent is to improve/evaluate an internal program. Therefore, there is no IRB determination or records for this survey. This is based on this definition of research from OHRP: **§46.102 Definitions for purposes of this policy.** (l) Research means a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge. Activities that meet this definition constitute research for purposes of this policy, whether or not they are conducted or supported under a program that is considered research for other purposes. For example, some demonstration and service programs may include research activities. <https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/revise-common-rule-regulatory-text/index.html#46.102>.”

There is no official waiver letter to provide as the NMDP IRB does not issue official determination letters for activities they do not have jurisdiction over (in this case, non-research activities). However, this response was reviewed by the NMDP IRB Administrator.

### **11. Justification for Sensitive Questions**

The survey does not include sensitive questions as defined by OMB guidelines (i.e., sexual practices, alcohol or drug use, religious preferences, etc.) nor does it request the respondent’s social security number (SSN). The survey does not ask for demographic information, however through NMDP’s unique donor identification numbers, we can categorize survey responses by race and ethnicity, gender, and age. This data is important for characterizing the donors to understand if support needs vary by segment.

### **12. Estimates of Annualized Hour and Cost Burden**

Respondents will include blood stem cell donors facilitated by NMDP and identified Network Partners.

#### **12A. Estimated Annualized Burden Hours**

Type of Respondent	Form Name	No. of Respondents	No. Responses per Respondent	Average Burden per Response (in hours)	Total Burden Hours
Blood Stem Cell Donors	Be The Match® Donation Experience Survey	1,672 (of 3,159 sent)	1	8 minutes (.13 hrs.)	217
<b>Total</b>		1,672 (of 3,159 sent)	1	8 minutes (.13 hrs.)	217

Respondent calculation estimates are based on volumes from the current post-donation survey (Be The Match® Donation Experience Survey) distribution in 2022 and the current response rate of approximately 53 percent. Burden hours were calculated via the Qualtrics survey tool, upon programming the survey a time estimate for completion was provided.

**12B.**

Provide estimates of annualized cost to respondents for the hour burdens for collections of information, identifying and using appropriate wage rate categories. This is the cost for respondents' time. The Department of Labor website can be used to determine appropriate wage rates for respondents (<http://www.bls.gov/bls/blswage.htm>).

The <http://www.bls.gov/bls/blswage.htm> website was used as the source to determine appropriate estimated wage rates for respondents. The wage rate was calculated using the May 2022 National Occupational Employment and Wage Estimates, United States ([https://www.bls.gov/oes/current/oes\\_nat.htm](https://www.bls.gov/oes/current/oes_nat.htm)). Estimates are calculated with data collected from employers in all industry sectors in metropolitan and non-metropolitan areas in every state and the District of Columbia for all occupations.

**Estimated Annualized Burden Costs**

Type of	Total	Hourly	Total
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<b>Respondent</b>	<b>Burden Hours</b>	<b>Wage Rate</b>	<b>Respondent Costs</b>
Blood Stem Cell Donors	217	\$22.26	\$4,830.42
Total			\$4,830.42

**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**

The surveys are administered by NMDP staff. The estimated average annual cost to the government is \$6,204.00, which includes efforts from staff in donor advocacy, donor experience, market research, and network/shared services, totaling approximately 11 hours per month or .07 FTE. The NMDP Finance department provided data to use as the source to determine appropriate estimated average wage rates for staff.

**15. Explanation for Program Changes or Adjustments**

The burden has changed nominally from the burden shown in the current inventory, estimated responses have increased minimally from 1,625 to 1,672 likely due to growth in overall donor volume and time burden reflects a more accurate total (218 hours to 217 hours) based on calculations.

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

Ongoing data collection will utilize Qualtrics software. NMDP program staff will analyze survey data. Survey results will be reviewed by the NMDP Donor Experience Manager and Senior Donor Advocacy Specialist and shared with internal functional leaders for the resolution of issues as appropriate. Results are also reported to network partners monthly via a dashboard template. Distribution numbers, response rates, and overall satisfaction scores will be reported to HRSA by way of the standard semi-annual progress reports. A three-year clearance for this recurring data collection is being requested.

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

The OMB number and expiration date will be displayed on every page of every form/instrument.

**18. Exceptions to Certification for Paperwork Reduction Act Submissions**

There are no exceptions to the certification.