

# Supporting Statement A

## Be The Match<sup>®</sup> Patient Support Center Survey

### OMB Control No. 0906 - Revision

**Terms of Clearance:** None

#### **A. Justification**

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

This is a request for Office of Management and Budget (OMB) continued approval of Be The Match<sup>®</sup> Patient Support Center survey. The C.W. Bill Young Cell Transplantation Program (Program) was established by the Stem Cell Therapeutic and Research Act of 2005 (Public Law 109 - 129) and was reauthorized in 2015 (P.L. 114 - 104). The Program's Office of Patient Advocacy/Single Point of Access is operated by the National Marrow Donor Program<sup>®</sup> (NMDP)/Be The Match<sup>®</sup>. NMDP/Be The Match<sup>®</sup> has explicit requirements to conduct surveys of patient satisfaction. As such, NMDP/Be The Match<sup>®</sup> department of Patient and Health Professional Services (PHPS) will elicit feedback from marrow and cord blood transplant patients, caregivers, and family members who have had contact with PHPS for navigation services, educational information, and support. The survey also includes demographic questions to determine representativeness of findings.

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

Barriers restricting access to transplant-related care and educational information are multi-factorial. Feedback from participants is essential to understand the changing needs for services and information as well as to demonstrate the effectiveness of existing services. The primary use for information gathered through the survey is to determine the helpfulness of participants' initial contact with the Be The Match Blood and Marrow Transplant (BMT) Navigators and to identify areas for improvement in the delivery of services. The BMT Navigators are trained lay or licensed clinical social worker navigators, who respond to requests for information and support. Stakeholders (i.e., participants, program managers, Be The Match leadership, and HRSA) utilize this evaluation data to share patients' experiences as well as make program (by program managers and leadership) and resource allocation (by HRSA) decisions.

Web- and paper-based surveys will be administered to all participants (patients, caregivers, and family members) who contact the Be The Match Patient Support Center. All participants for whom an email address is known will be invited to complete the survey online. All other participants will be mailed a survey with a pre-paid reply envelope. Survey respondents will be notified via email invitation or cover letter and in the survey instructions that participation is voluntary and responses will be kept confidential. A follow-up invitation will be sent within 2 weeks to non-respondents.

The survey includes these items to measure: 1) reason for contacting the Be The Match Patient Support Center; 2) if the BMT Navigator was able to answer questions and easy to understand; 3) if the contact helped the participant to feel better prepared to discuss transplant with their care team; 4) increase in awareness of available resources; 5) timeliness of response; and 6) overall satisfaction. 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 biannually and implementation of resulting program changes will be documented.

*Revisions to the survey are noted in the comment fields on the attached instrument.*

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

The web-based survey will be administered via SNAP Survey to reduce respondent burden (508 compliant). 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. For those participants who do not have access to the internet, scannable paper surveys will be administered with self-addressed, pre-paid response envelopes.

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

The survey is designed to capture data that will measure the navigation program objectives. It has been reviewed carefully to avoid duplication. None of the questions are present on other evaluation instruments. The proposed survey is unique to this activity.

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

These surveys will not have a significant impact on small businesses or other small entities.

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

This survey is cross-sectional in design. To reduce burden, each patient, caregiver, or family member will be administered the survey one time only, even when multiple contacts between PHPS and the participant occur. If the participant contacts PHPS and the survey was administered 2 or more years previously, PHPS will administer another survey. It is likely that available resources, services, and delivery methods will have changed and new feedback will be important for evaluating the effectiveness of the services.

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

The request fully complies with 5 CFR 1320.5.

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

### **Section 8A:**

A 60-day *Federal Register* notice was published on August 8, 2017, vol. 82, No. 151; pp. 37103-37104. No comments were received.

### **Section 8B:**

The National Marrow Donor Program/Be The Match<sup>®</sup> Patient Services Advisory Group (advisory group the Board of Directors) reviews results of this survey annually. The advisory group is comprised of blood and marrow transplant survivors, caregivers, health professionals, and patient advocates. No major problems with the instrument or results were identified.

## **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 and/or mailing 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. A unique identifier is assigned to each participant for survey response tracking only. The data manager and data analyst do not have cross-linking access to the separate databases. All staff involved in the administration, analysis, and reporting of data are CITI (Collaborative Institutional Training Initiative) certified for human subjects research. While this is considered evaluation, not human subjects research, the NMDP IRB has previously reviewed this procedure for protection of humans and deemed it acceptable.

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. Completed surveys are stored electronically on a secure server at NMDP/Be The Match<sup>®</sup> for 5 years for trends analyses and are then destroyed.

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

The survey includes questions about the respondents' race and ethnicity. This data is important for characterizing the population served, describing representativeness of results, and identifying disparities in utilization of PHPS services. The questions are optional and include a "Decline to answer" response option. No other sensitive items are included in this survey.

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

*Respondents:*

Respondents will include all patients, caregivers, and family members who have contact with the Patient Support Center via phone or email for BMT navigation services and support (advocacy). The decision to survey all participants was made based on the historically low response rate to this survey due to patients' frequent transitions in health status as well as transfer between home and the hospital for initial treatment and care for complications.

*Planned frequency of information collection:*

Participants will receive the survey only one-time in a 2-year cycle. If a participant contacts the Patient Support Center 2 or more years after the initial contact, he or she will receive a second survey. This is because we anticipate that the participants' needs, technology, available services, and delivery methods have likely changed during the time lapse.

*Annual burden estimates:*

The total respondent burden for the telephone-based customer satisfaction surveys is estimated to be 105 hours. HRSA expects a total of 420 respondents (33% response rate) to complete the Be The Match® Patient Support Center Survey.

**12A. Estimated Annualized Burden Hours**

<b>Type of Respondent</b>	<b>Form Name</b>	<b>No. of Respondents</b>	<b>No. Responses per Respondent</b>	<b>Total Responses</b>	<b>Average Burden per Response (in hours)</b>	<b>Total Burden Hours</b>
<b>Patients, caregivers and family members</b>	Patient Support Center Survey	420	1	420	.25	105
<b>Total</b>		420		420		105

The average burden per response is based on findings from a pilot of the survey conducted in 2012.

## **12B. Estimated Annualized Burden Costs**

<b>Type of Respondent</b>	<b>Total Burden Hours</b>	<b>Hourly Wage Rate</b>	<b>Total Respondent Costs</b>
<b>Patients, caregivers and family members</b>	105	\$22.33	\$2,345.00
<b>Total</b>	105		\$2,345.00

It is estimated that the annualized burden costs for the Patient Services Survey will be \$2,345.

\*Based on 2016 National Occupation and Wage Statistics  
([https://www.bls.gov/oes/current/oes\\_nat.htm](https://www.bls.gov/oes/current/oes_nat.htm))

## **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 will be administered by Patient Health Professional Services' staff. The estimated annual cost to the government is \$19,464, which includes effort from: Evaluation Research Specialist (.20 FTE; \$9,364), Patient Support Center Administrative Assistant (.15 FTE; \$6,050), Senior Evaluation Specialist (.05 FTE; \$4,050).\*

\*Based on 2016 National Occupation and Wage Statistics  
([https://www.bls.gov/oes/current/oes\\_nat.htm](https://www.bls.gov/oes/current/oes_nat.htm))

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

This is a new information request.

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

Ongoing data collection will utilize Snap Survey software for scannable paper surveys, entered and stored in a secure Excel database, and analyzed using SPSS and/or SAS. Program staff will conduct descriptive analysis and/or modeling of survey data. Survey results will be reported in aggregate to stakeholders via quarterly and annual research briefs, quarterly report against performance standards, and potentially in relevant peer-reviewed publications.

**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.