Supporting Statement A

Be The Match® Patient Support Center Survey

OMB Control No. 0906–0004 - 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 the Be The Match® 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® (NMDP)/Be The Match®). NMDP/Be The Match® has explicit requirements to conduct surveys of patient satisfaction. As such, NMDP/Be The Match® will elicit feedback from marrow and cord blood transplant patients, caregivers, and family members who had contact with the Be The Match® Patient Support Center 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 two weeks to non-respondents.

The survey will include these items to measure: 1) overall satisfaction; 2) if the contact helped

the participant feel more confident in coping with treatment; 3) if the contact helped the participant feel more hopeful; 4) if the contact helped the participant feel less alone; 5) increased awareness of available resources; 6) if the contact helped the participant feel more informed about treatment options; 7) reason for contacting the Be The Match Patient Support Center; 8) how participant learned about the Patient Support Center; 9) actions taken by participant as a result of the contact, and 10) types of challenges faced by participant. 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 or additions will be documented.

For this revised information collection request, the proposed changes to the survey instrument include minor changes to selected questions and a reduction in the overall number of questions. See the attached redlined surveys in English and Spanish for the proposed changes.

3. Use of Improved Information Technology and Burden Reduction

The web-based survey will be administered via Qualtrics 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 Patient Support Center and the participant occur. If the participant contacts Patient Support Center and the survey was administered, two or more years previously, Patient Support Center will administer another survey. Available resources, services, and delivery methods will likely 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

A 60-day *Federal Register* notice was published on May 4, 2020, vol. 85, No. 86; pp. 26483-84. No comments were received.

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 to administer 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. 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 entirely 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® for up to years for trends analyses and are then destroyed.

11. Justification for Sensitive Questions

The survey includes questions about the respondents' gender, race, and ethnicity. This data is important for characterizing the population served, describing representativeness of results, and identifying disparities in utilization of Patient Support Center services. The answers are voluntary, and 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 one time in a one-year cycle. If a participant contacts the Patient Support Center one 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 customer satisfaction surveys is estimated to be 220 hours. HRSA expects a total of 1,320 respondents to complete the Be The Match® Patient Support Center Survey.

12A. Estimated Annualized Burden Hours

Form Name	Number of Respondents	Number of Responses per Respondent	Total Responses	Average Burden per Respondent (in hours)	Total Burden Hours
Be The Match® Patient Support Center Survey	1,320	1	1,320	0.167*	220**

*Decreased from .25 average burden per response as published in the May 4, 2020 60-day FRN.
**Decreased from 680 total burden hours as published in the May 4, 2020 60-day FRN due to a reduction in the estimated number of respondents.

12B. Estimated Annualized Burden Costs

Type of Respondent	Total Burden Hours	Hourly Wage Rate	Total Respondent Costs
Patients, caregivers and family members	220	$27.52	$6,054.40
Total	220		$6,054.40

It is estimated that the annualized burden costs for the Patient Services Survey will be $6,054.40.

*The Department of Labor website (http://www.bls.gov/bls/blswage.htm) was used to determine appropriate wage rates for respondents. Wage rate was calculated using the Quarterly Census Employment and Wages, 2018 annual averages for all industries, all states,

and all establishment sizes.

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 NMDP/Be The Match®, a HRSA contractor for the C.W. Bill Young Cell Transplantation Program's Office of Patient Advocacy contract Patient Support Center's staff. The estimated annual cost to the government is $20,978.70 which includes effort from the following: Evaluation Research Specialist (.2 FTE; $13,152), Patient Support Center Administrative Assistant (.15 FTE; $6,511.50), Evaluation and Analysis Specialist (.02 FTE; $1,315.20).*

*Based on 2018 National Occupation and Wage Statistics (http://www.bls.gov/bls/blswage.htm)

15. Explanation for Program Changes or Adjustments

The current burden inventory is 105 hours and this request is for 220 hours due to an increase in the estimated number of responses.

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

Ongoing data collection will utilize Qualtrics 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 bi-annual research briefs, quarterly report against performance standards, and potentially in relevant peer-reviewed publications. Findings will only be used for program improvement and will not be generalizable. We request a three year clearance for this survey.

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.