

Supporting Statement A
Be The Match® Patient Services Survey
OMB Control No. 0906-xxxx - NEW

Terms of Clearance: None

A. Justification

1. Circumstances Making the Collection of Information Necessary

This is a request for OMB approval of a voluntary quantitative customer satisfaction survey titled, Be The Match® Patient Services Survey, under HRSA's generic clearance. 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 reauthorized in 2010 (P.L. 111 - 264). The Program's Office of Patient Advocacy/Single Point of Access is operated by National Marrow Donor Program® (NMDP)/Be The Match®. NMDP/Be The Match® has explicit requirements to conduct surveys of patient satisfaction (HRSA contract #HSH250201200017C, Task 4f). As such, NMDP/Be The Match® 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 better 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 helpfulness of participants' initial contact with the PHPS Patient Services Coordinators (PSCs) and to identify areas for improvement in the delivery of services. The PSCs are trained navigators, most are licensed clinical social workers, who respond to requests for information and support. Stakeholders (i.e., participants, program managers, PHPS leadership, and HRSA) utilize this evaluation data to share their patients' experiences as well as make program (by program managers and PHPS 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 PHPS PSCs. 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 will include these items to measure: 1) reason for contacting PHPS; 2) if the PSC 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 (per contract deliverable #19). Feedback indicating a need for improvement will be reviewed by program managers biannually and implementation of resulting program changes will be documented. Copies of the survey instruments are included (Attachment D).

3. Use of Improved Information Technology and Burden Reduction

The web-based survey will be administered via SurveyGizmo to reduce respondent burden. SurveyGizmo is 508 compliant. This technology allows PHPS to send reminders 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, 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. Each patient, caregiver, or family member will be administered the survey one-time only, even when multiple contacts between PHPS and the participant occur, to reduce burden. 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. **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 60 day Federal Register Notice was published in the *Federal Register* on August 14, 2014, vol. 79, No. 157; pp. 47656-57.

Section 8B:

The National Marrow Donor Program/Be The Match® 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 (see attachment C). The most recent review occurred in April 2014. No major problems with the instrument or results were identified that could not be resolved.

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 address for the purpose of administering the survey only and will fully comply with the Privacy Act. Separate databases are used for 1) participant names and addresses versus; and 2) 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 certified. 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® for 5 years for trends analyses and 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 PHPS via phone or email for transplant 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 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 PHPS 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. We expect a total of 420 respondents (33% response rate) to complete the Be The Match® Patient Services Survey.

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
Patients, caregivers and family members	Patient Services Survey	420	1	15/60	105
Total					105

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

12B. Estimated Annualized Burden Costs

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

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

*Mean US hourly wage retrieved from http://www.bls.gov/oes/2013/may/oes_nat.htm (May 2013)

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 PHPS staff. The estimated annual cost to the government is \$33,803.05, which includes effort from: HSR Specialist (.20 FTE; \$10,976), HSR Assistant (.10 FTE; \$3,900), Patient Services Administrative Assistant (.15 FTE; \$5,265), Senior Evaluation Specialist (.05 FTE; \$3,200), Senior Manager, HSR (.05 FTE; \$4,617), and federal staff (COR), a GS13/ Step 10: (.05 FTE; \$5,845.05)

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 SurveyGizmo and Snap Survey software for scannable paper surveys, entered and stored in a secure Excel database, and analyzed using SPSS and/or SAS. PHPS 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. Findings will only be used for program improvement and will not be generalizable. We request a 3 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.