



Billing Code 4165-15-P

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Agency Information Collection Activities: Proposed Collection: Public Comment Request

Information Collection Request Title: Be The Match[®] Patient Support Center Survey

OMB No. 0906-0004 - Revision

AGENCY: Health Resources and Services Administration (HRSA), Department of Health and Human Services.

ACTION: Notice.

SUMMARY: In compliance with the requirement for opportunity for public comment on proposed data collection projects of the Paperwork Reduction Act of 1995, HRSA announces plans to submit an Information Collection Request (ICR), described below, to the Office of Management and Budget (OMB). Prior to submitting the ICR to OMB, HRSA seeks comments from the public regarding the burden estimate, below, or any other aspect of the ICR.

DATES: Comments on this ICR should be received no later than **[INSERT DATE 60 DAYS AFTER DATE OF PUBLICATION IN THE *FEDERAL REGISTER*]**.

ADDRESSES: Submit your comments to paperwork@hrsa.gov

FOR FURTHER INFORMATION CONTACT: To request more information on the proposed project or to obtain a copy of the data collection plans and draft instruments, email paperwork@hrsa.gov or call Lisa Wright-Solomon, the HRSA Information Collection Clearance Officer at (301) 443-1984.

SUPPLEMENTARY INFORMATION: When submitting comments or requesting information, please include the ICR title for reference.

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Abstract: 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 is operated by the National Marrow Donor Program[®] (NMDP)/Be The Match[®]. NMDP/Be The Match[®] has specific requirements under its HRSA contract to conduct surveys to assess 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 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 as well as opportunities for the development of new programs and services.

Need and Proposed Use of the Information: 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 Certified Oncology Patients or Nurse Navigators, who respond to requests for information and support. Stakeholders (e.g., participants, program managers, Be The Match® leadership, and HRSA) use this evaluation data to share patients' experiences as well as make program (by program managers and leadership) and resource allocation (by HRSA) decisions.

Online and paper-based surveys will be administered to all participants (patients, caregivers, and family members) who have contact with the Be The Match® Patient Support Center. All participants that provided an email address 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 and cover letter and informed in the survey instructions that participation is voluntary, and responses will be kept confidential. A follow-up notification

will be sent within two (2) weeks to non-respondents. The survey will be available in English and Spanish languages.

The survey will measure: (1) overall satisfaction; (2) if the contact helped the participant feel more confident in coping with the area of concern regarding the call; (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) if participant's questions were answered through contact with the Be The Match® Patient Support Center, and (8) types of challenges faced by participant. The survey data will be analyzed quarterly and rolled up for an annualized analysis. The results of the analyses will be shared with program managers and HRSA. Feedback indicating a need for improvement will be reviewed by program managers biannually, and implementation of results, program changes, or additions will be documented.

Proposed changes to the survey instrument include minor changes to selected questions and a reduction in the overall number of questions. The estimated amount of respondents will increase as it will be easier for them to complete the survey online. As a result of fewer questions along with the addition of an online platform, the respondent's burden will decrease.

Likely Respondents: Respondents will include all patients, caregivers, and family members who have contact with Be The Match® Patient Services Coordinators via phone or email for transplant navigation services and support. The decision to survey all participants was made based on historical evidence of patients' unavailability due to frequent transitions in health

status.

Burden Statement: Burden in this context means the time expended by persons to generate, maintain, retain, disclose, or provide the information requested. This includes the time needed to review instructions; to develop, acquire, install and utilize technology and systems for the purpose of collecting, validating and verifying information, processing and maintaining information as well as disclosing and providing information; to train personnel and to be able to respond to a collection of information; to search data sources; to complete and review the collection of information; and to transmit or otherwise disclose the information. The total annual burden hours estimated for this ICR are summarized in the table below.

Total 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	4,000	1	4,000	0.17*	680**
Total					

*Decreased from .25 burden per respondent

**Increased from 105 hours but due to an almost tenfold increase in number of respondents HRSA specifically requests comments on (1) the necessity and utility of the proposed information collection for the proper performance of the agency's functions, (2) the accuracy of the estimated burden, (3) ways to enhance the quality, utility, and clarity of the information to be collected, and (4) the use of automated collection techniques or other forms of information technology to minimize the information collection burden.

Maria G. Button,

Director, Executive Secretariat.

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