



Billing Code 4165-15

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

**Agency Information Collection Activities: Proposed Collection: Public Comment Request
Information Collection Request Title: Office of Patient Advocacy/Be The Match® Patient
Services 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 must 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* or mail the HRSA Information Collection Clearance Officer, Room 14N39, 5600 Fishers Lane, Rockville, MD 20857.

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 the HRSA Information Collection Clearance Officer at (301) 443-1984.

SUPPLEMENTARY INFORMATION: When submitting comments or requesting information, please include the information request collection title for reference, in compliance with Section 3506(c)(2)(A) of the Paperwork Reduction Act of 1995.

Information Collection Request Title: Office of Patient Advocacy/Be The Match®
Patient Services Survey OMB No. 0906-0004 – Revision

Abstract: The National Marrow Donor Program®/Be The Match® is a HRSA contractor dedicated to helping patients and families get the support and information they need to learn about their disease and treatment options, prepare for a blood stem cell transplant, and thrive after a transplant procedure. The information and resources provided help individuals navigate the bone marrow or cord blood transplant process. Participant feedback is essential to understand the needs for transplant support services and educational information across a diverse population. This information is used to determine helpfulness of existing services and resources. Feedback is also used to identify areas for improvement and develop future programs.

Need and Proposed Use of the Information: Barriers to access to bone marrow or cord blood 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 Be The Match® Patient Services Coordinators (PSC) and to identify areas for improvement in the delivery of services. In addition, stakeholders use this evaluation data to make program and resource allocation decisions.

The survey includes items to measure the following: 1) reason for contacting Be The Match®, 2)

if the PSC was able to answer questions and was easy to understand, 3) if the contact helped the participant to feel better prepared to discuss transplants with their care team, 4) increase in awareness of available resources, 5) timeliness of response, and 6) overall satisfaction.

The proposed changes to the survey instrument include minor changes to both selected survey questions and the instructions. The updated survey questions include simplified language and the references to race and ethnicity are updated to better match preliminary U.S. Census Bureau question format and statements from the U.S. Department of Education. The question format changes will better allow individuals to self-identify their ethnicity and race and permit individuals to select more than one race and/or ethnicity. These changes will not increase respondent burden.

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 historic evidence of patients' unavailability due to frequent transitions in health status as well as between home and the hospital for initial treatment and care for complications.

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, and 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 Response (in hours)	Total Burden Hours
Be The Match Patient Services Survey	420	1	420	0.25	105
Total	420		420		105

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.

Amy McNulty,

Acting Director, Division of the Executive Secretariat.

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