Health Resources and Services Administration SUPPORTING STATEMENT Confirmatory Typing Survey

A. Justification

1. <u>Circumstances of Information Collection</u>

The Health Resources and Services Administration (HRSA) currently has approval under the generic clearance, Office of Management and Budget (OMB) Control No. 0915-0212, to conduct customer satisfaction surveys and focus groups. This collection of information helps fulfill the requirements of:

a. Executive Order 12862, "Setting Customer Service Standards," which directs Agencies to continually reform their management practices and operations to provide service to the public that matches or exceeds the best service available in the private sector.

This is a request for OMB approval of a qualitative voluntary customer satisfaction survey or focus group under HRSA's generic clearance. This survey will be used to determine what information potential donors need to remain connected, engaged and informed about the donation process. This information will be used to identify potential gaps in the communication and also any other areas of improvement that can be made to enhance the potential donor experience throughout the process.

Executive Order 12862 directs agencies that "provide significant services directly to the public" to "survey customers to determine the kind and quality of services they want and their level of satisfaction with existing services". The objective of surveying the potential donor is to provide insight regarding their opinions, experiences and perceptions of the confirmatory typing process including any barriers or restrictions of moving forward if called as a match for a patient and asked to donate via PBSC or marrow.

2. <u>Purpose and Use of the Information</u>

Confirmatory typing is the process to obtain blood samples from a potential donor that would be used for confirmatory HLA typing at the transplant center laboratory and infectious disease testing. These results are then used for determination by the transplant center if this is a donor they would request to donate.

The information obtained through the Confirmatory Typing Survey will be used to measure potential donors' overall satisfaction of their experience throughout the confirmatory typing process. If a trend is identified within a specific area that warrants improvement, project groups will be initiated to address those areas. Surveys will continue to be completed to ensure that we are continually improving the experience for potential donors moving through the confirmatory typing process.

A small pilot test of this survey was completed in summer 2012. Based on the information obtained, a gap in communication was identified between the time the potential donor gave their confirmatory typing sample and when they received resolution (i.e. hearing that they were not the best match for the patient). Project teams were formed around this particular area and additional tool kits and verbiage were developed to assist the potential donor with this understanding and gap in the process. A few of those toolkits included providing acknowledgement that their steps were completed and now we are just waiting for the transplant center to provide additional direction. We also improved the communication mechanism in which we share with the potential donor that they are not the best match for this patient. The project group also established additional educational resources for the potential donor to explore when waiting for the next step in the process.

3. <u>Use of Improved Information Technology</u>

This survey will be completed by respondents using secure online technology. The majority of the questions are responded to using a Likert scale (very good, good, neutral, poor, very poor, I do not remember) or true/false response, where the potential donor rates how they felt about particular interactions or experiences within the confirmatory typing process. The other questions are free text where potential donors are able to provide their feedback on a voluntary basis if there is something more specific they would like to share with Be The Match. Due to the use of the electronic distribution this survey will only be sent to those potential donors that have provided an email address which is on file with Be The Match. At this time the survey will not be translated into languages other than English. Knowing we have a diverse registry, dependent on funding, feasibility and technology, translation of the survey may be explored in the future.

This survey should take the respondents approximately 15 minutes. There are 12 questions in the survey with sub-sections within each question. Be The Match will prepopulate several fields of the survey with information the potential donor provided at recruitment. Since the pilot of this survey, the total number of questions has been reduced, the opportunities to provide free text has been streamlined and made optional. These metrics in addition to the use of the electronic survey will ensure that the survey can be taken as efficiently as possible for the potential donor.

4. <u>Efforts to Avoid Duplication</u>

Currently no other surveys distributed by Be The Match registry request information from potential donors regarding the confirmatory typing process. If a potential donor is selected and proceeds through PBSC or marrow donation there is a "Post Donation Satisfaction" survey that is distributed. Typically the potential donors completing the "Post Donation Satisfaction Survey" would not be surveyed through this confirmatory typing survey.

The purpose of the "Post Donation Satisfaction Survey" is to determine how satisfied potential donors are with their donation experience and to identify areas for improvement. The focus is on the quality of the potential donor experience and retention. The results will be utilized to develop strategic initiatives and to provide feedback to participating Network centers on their performance.

The purpose of the Confirmatory Typing survey will be to measure potential donors' overall satisfaction of their experience throughout the confirmatory typing process. The results will be utilized to develop strategic initiatives including process improvements or tool development.

5. <u>Involvement of Small Entities</u>

The data collected will be from individual potential Marrow or PBSC donors. Part of the CT survey will be prepopulated based on information (i.e. potential donor demographics) in our electronic database which was provided by the potential donors upon recruitment. This prepopulated information will not be visible to the respondent and will only be used to distinguish if trending exists based on potential donor attributes such as age or sex. Additionally the survey includes prepopulated information about the respondents' race and ethnicity. This data is important for characterizing the population served and describing representativeness of results.

The information being requested has been held to the minimum required for the intended use of the data. Completion of the survey is voluntary.

No small businesses will be involved in this study.

6. <u>Consequences if Information Collected Less Frequently</u>

The survey will only be distributed once per confirmatory typing appointment, upon release of the potential donor from the patient's search (i.e. hearing that they were not the best match for the patient). If the potential donor moves onto the workup stage immediately they will be excluded from this data set.

7. <u>Consistency With the Guidelines in 5 CFR 1320.5(d)(2)</u>

These surveys will be implemented in a manner fully consistent with 5 CFR 1320.5(d)(2).

8. <u>Consultation Outside the Agency</u>

In accordance with 5 CFR 1320.8(d), on June 5, 2012, a 30 day notice was published in the Federal Register for HRSA's generic clearance, OMB Control No. 0915-0212 (Vol. 77, Page 33224). No public comments were received.

This survey was not developed with outside consultation from any agency. The instrument was developed by staff within Be The Match registry and approved by program managers and leadership. The survey will be delivered via a secure subscription based online survey distributor that allows us to create and deploy surveys using their survey suite and allows us to view and analyze data and build reports.

9. <u>Remuneration of Respondents</u>

No payments or gifts will be provided to the respondents.

10. <u>Assurance of Confidentiality</u>

To date, the HRSA customer satisfaction surveys have not collected personally identifiable information from respondents. Data will be kept private to the extent allowed by law.

11. <u>Questions of a Sensitive Nature</u>

The potential donor's race and ethnicity is provided by the potential donor at the registration stage. This information, which was provided by the potential donor, will be prepopulated into the survey and will be suppressed from the potential donor's view. This data is important for characterizing the population served and describing representativeness of results. It is also important to allow Be The Match Registry to cater to those unique needs of our potential donor audience.

12. Estimates of Annualized Hour Burden

Respondents:

All potential donors that complete the confirmatory typing process that do not move onto donation of PBSC or marrow will be included in this survey. The survey will be distributed only to those potential donors speaking English and that have an email address on file that the survey can be sent to.

Annual burden estimates:

The total respondent burden for the secure online customer satisfaction surveys is estimated to be 652 hours. Based on the number of respondents to the pilot survey (completed in 2012), we anticipate an annual total of 2500 respondents (20% response rate) to complete the Be The Match Confirmatory Typing survey.

Type of Collection	Number of	Responses	Total	Hours per	Total	Wage	Total
	Respondents	per	Responses	Respondent	Burden	Rate	Hour Cost
		Respondent			Hours		
Be The Match Confirmatory Typing Survey	2500	1	2500	.25	625	\$22.33	\$13956
Total							\$13956

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

Planned frequency of information collection:

Participants will receive a survey each time they move to the confirmatory typing process if they do not move onto PBSC or marrow collection immediately following the blood sample collection. Currently participants are excluded if they have a language other than English listed as their preferred language and we do not have an email on file.

13. <u>Estimates of Annualized Cost Burden to Respondents</u>

The only associated cost to respondents is their time to respond to the survey questions.

14. Estimates of Annualized Cost to the Government

The surveys will be administered and analyzed by Donor and Cord Blood Management Services (DCBMS) staff. The estimated annual cost to deploy the survey will be covered by the Department's budget. The contractor anticipates no charge to the government. However, there will be costs associated with Federal staff (COR) processing the survey during its approval and implementation: GS13/ Step 10: (.03 FTE; \$3,542.07)

15. <u>Change in Burden</u>

This is a new activity under HRSA's generic clearance and will be included in the total burden currently approved by OMB under OMB Control No. 0915-0212.

16. <u>Plans for Analysis and Timetable of Key Activities</u>

Ongoing data collection will utilize Allegiance software for collection of electronic survey results. Allegiance software program is currently utilized for the "Post Donation Satisfaction Survey." DCBMS staff will conduct descriptive and/or multivariate analysis of survey data. Survey results will be reported in aggregate to stakeholders. Findings will only be used for program improvement.

17. Exemption for Display of Expiration Date

No exemption is being requested. The expiration date will be displayed.

18. <u>Certifications</u>

This information collection activity will comply with the requirements in 5 CFR 1320.9.