

Recommendations of the World Marrow Donor Association (WMDA) Registries Working Group: Recruitment, training, and ongoing educational requirements for donor registry search coordinators

INTRODUCTION

Identification of a suitable, unrelated adult donor or cord blood unit (CBU) for allogeneic hematopoietic stem cell (HSC) transplant requires the dynamic coordination of complex interactions between unrelated donor registries and transplant centres (TC) across the world to facilitate the identification, testing, and procurement of HSC on behalf of patients in need. Registry staff play a vital role in facilitating search-related requests, and it is critical that recruitment and training requirements of staff performing tasks requiring expertise and proficiency be consistent across WMDA participating registries to ensure expedition of search and standardization of care regardless of patient registry of origin. To this end, the WMDA Registries Working Group has sought to identify current registry practices for the recruitment and training of registry staff performing search coordinator duties, a relatively niche field that requires a breadth of expertise not often captured in a single academic curriculum.

BACKGROUND

In 2009, a survey aimed at understanding practices surrounding SC recruitment and training requirements was distributed to WMDA-accredited registries; feedback was ultimately received from 16 registries, providing insight towards the recommendations outlined by the WMDA Donor Registries Working Group in 2011 (Evseeva et al., 2011). Responsibilities were demonstrated to comprise a heterogeneous group of activities which varied among participating registries due to factors registry size, structure, national TC dynamics, and number of patients served. Proposal of a single set of recruitment and training requirements thus posed a challenge due to the intricate and variable nature of the registry SC role. To this end, requirements for staff performing various activities, such as database search, HLA-matching, and donor selection were presented distinctly with the observation that there is often overlap among these responsibilities and that the scope of SC activity will often encompass responsibilities not addressed in the survey. It was found that a university-level degree in health sciences, such as bachelor's degree in science, health sciences, or nursing, is desirable for staff who perform basic SC responsibilities and highly-encouraged for those whose responsibilities include donor selection and/or require HLA expertise. Further, the need for a standardized, global training modality was identified to complement the recruitment requirement and in-house training of staff who will perform allogeneic search-related activities.

The decade that has elapsed since the previous survey's dissemination has seen many changes in the global HSC transplant community landscape; the number of donors represented in the WMDA database now exceeds 40 million donors with over 100 participating registries in 57 countries. Improvement in registrant typing methods has decreased ambiguity among new registrant HLA profiles, expediting the identification of histocompatible donors for transplant, while international access to donors has increased due to improvements in information technology infrastructure and increased collaboration among registries via networks such the European Marrow Donor Information System. Integration of the Bone Marrow Donors Worldwide global donor database with WMDA and

implementation of a new Search & Match Service has increased the opportunity for evaluation of donors from all participating registries. Prognostication of donor match at ambiguous HLA loci and display of non-HLA donor characteristics, including gender, age, ABO group, and CMV serostatus, are now presented allowing for more robust evaluation of all international donors. Finally, since 2015 the WMDA has offered the Search Coordinator Certificate Programme, an expert-led, web-based curriculum aimed at providing comprehensive training for the HSC transplant community at Basic, Advanced, and Ongoing levels. It was thus timely to reassess the impact that these developments have had on registries' recruitment and training requirements for staff who fulfill these essential search coordination roles.

Since the Working Group has identified a heterogeneity and breadth of tasks comprising the SC role, it has further been the ambition of this initiative to clarify and define the stages of the allogeneic search process, highlighting roles and responsibilities therein. Consistency in terminology used to describe registry activities will further support the standardization of both registry staff roles and the requisite training and education essential for their fulfillment. The registry SC has thus been defined ***as unrelated donor registry staff member whose responsibilities may include, but are not necessarily limited to, activities surrounding the preliminary and formal stages of unrelated allogeneic HSC search on behalf of patients seeking transplant. The SC role could include activities such as query of allogeneic donor/CBU databases, identification of potential donors/CBUs for further HLA typing, provision of immunogenetic services (search strategy and donor/CBU selection support), and/or graft selection.*** An overview of registry search processes and accompanying list of definitions has thus been described (**Figure 1** and **Table 1**).

SURVEY SUMMARY

The survey invitation was extended via email to designated contacts at all WMDA-participating registries to increase both the number and diversity of responses compared with 2009. The survey was also featured under the pillar of 'Supporting Global Development' in Stem Cells Matters Issues 45 (August 2019) inviting registries to participate via embedded link; further reminders surrounding the survey and participation deadlines were included in Issues 46 though 48. The Survey was accessible for a period of two months, concluding October 31, 2019.

References:

Evseeva, I., Ciffey, K., Morsch, S., and Parguey, V. WMDA donor registries working group recommendations on the training of staff performing patient-donor search and HLA matching activities. 2011. WMDA Standard 2.07 available online: <https://share.wmda.info>

Wiegand, T., Raffoux, C., Hurley, C.K., Kern, M., Oudshoorn, M., Raymond, J., Cleaver, S., Marry, E., and Muller, C. A special report: suggested procedures for international unrelated donor search from the donor registries and quality assurance working groups of the World Marrow Donor Association (WMDA). *Bone Marrow Transplant* 2004; **34**: 97-101.

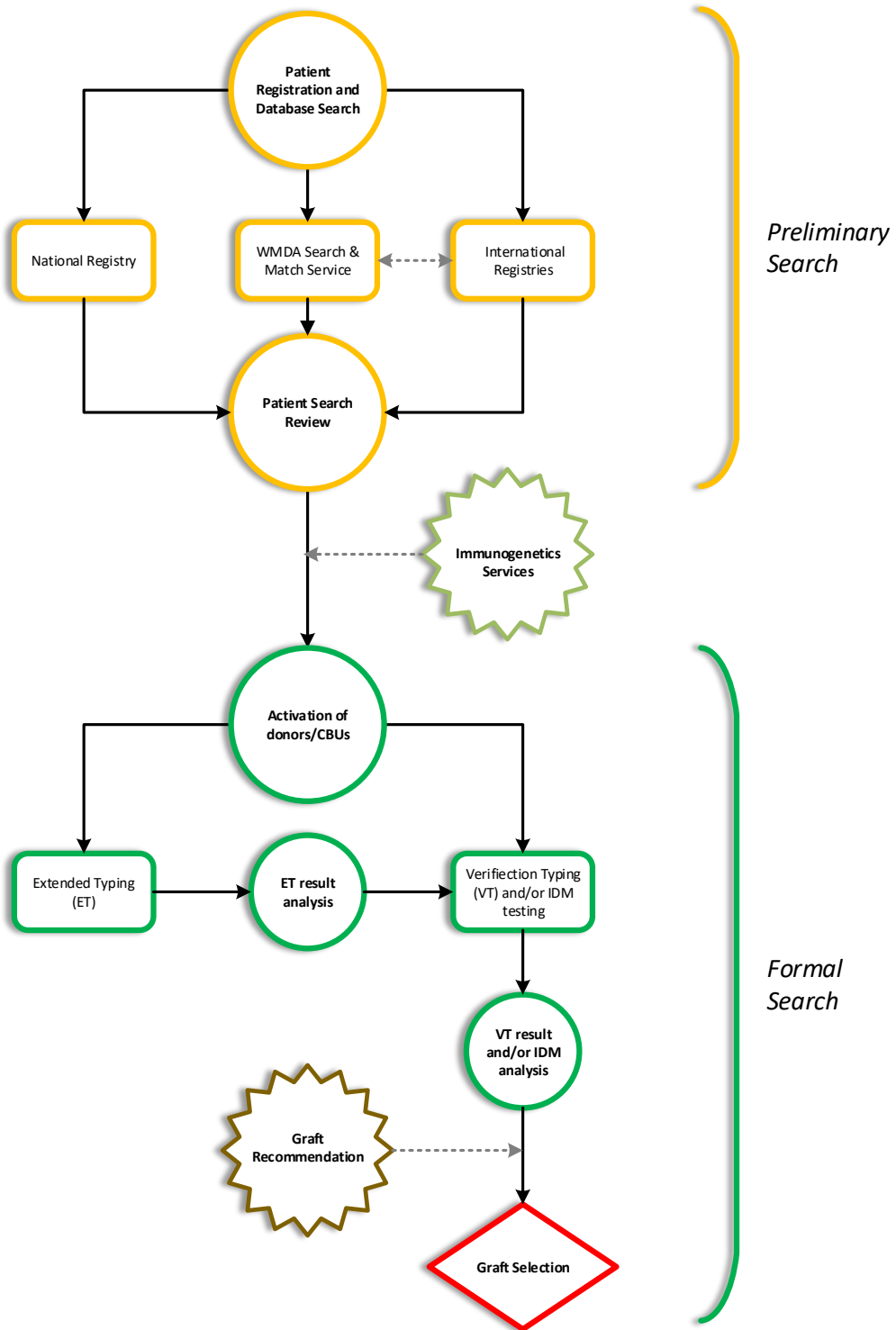


Figure 1: Overview of the allogeneic hematopoietic stem cell search process. Stages of the preliminary (yellow) and formal (green) search are highlighted.

Survey Definitions

Search Coordinator (SC): An unrelated donor registry staff member whose responsibilities may include, but are not necessarily limited to, activities surrounding the preliminary and formal stages of unrelated allogeneic HSC search on behalf of patients seeking transplant. The SC role could include activities such as query of allogeneic donor/CBU databases, identification of potential donors/CBUs for further HLA typing, provision of immunogenetic services (search strategy and donor/CBU selection support), and/or graft selection.

Preliminary Search: Process by which a patient in need of allogeneic HSC transplant is registered by his/her national registry so that domestic and international databases may be queried to identify an HLA-compatible volunteer donor or CBU for transplant as described by Wiegand et al. (2004).

Formal Search: Process by which one or more donor or CBU HLA typing requests is initiated to identify and confirm the availability of suitable donors/CBUs for HSC transplant (Wiegand et al., 2004).

Extended HLA typing (ET): HLA testing, typically performed on repository samples stored by the donor registry or cord blood bank (CBB), that is requested in order to obtain typing results at one or more missing or ambiguous HLA locus/loci so that match level between a recipient and donor/CBU can be assessed.

Verification typing (VT): HLA testing performed on a fresh blood sample procured from a histocompatible donor to confirm identity prior to transplant. Sometimes referred to as “confirmatory typing”.

Search Coordinator Certificate Programme (SCCP): Course offered by the World Marrow Donor Association to educate and increase proficiency in areas related to allogeneic search coordination. It is offered at both the Basic and Advanced levels.

Educational requirement: Professional certificate or diploma refers to any college diploma, trade, or professional certification or national equivalent. Health science degree refers to those obtained from accredited universities in fields such as science (BSc.), health science, or nursing. Graduate-level degrees refer to those typically obtained following successful completion of a related university degree; examples include MSc., PhD., and MD.

Structured training program: A program administered by a registry to ensure consistency in the training of employees towards proficiency in a new role. The program might include review of standard operating procedures, a supervision period, competency/proficiency testing, supervisory review or a combination of these elements.

Experience: Post-recruitment, ‘on-the-job’ training and practice required to achieve proficiency at a specific SC function. Occurs outside of the structured training program and typically requires support, supervision, and/or oversight.

Database search: refers to the query of unrelated donor registry and/or CBB databases with the patient’s HLA genotype to identify potential donors/CBUs based on HLA match probability. Database searches may

include domestic registry, WMDA Search & Match Service, and/or European Marrow Donor Information System (EMDIS)-mediated searches.

Search review: Identification of potential graft options for further investigation (ET and/or VT) following examination of search reports obtained during preliminary search. Selection of grafts for further testing might consider both HLA and non-HLA donor/CBU characteristics. The search coordinator could be responsible for making recommendations to transplant centres or for **selection of donors/CBUs for ET/VT**.

Immunogenetics services: Services that support patient search which require advanced knowledge of HLA, histocompatibility, and donor/CBU search processes. Preparation of patient search advisory reports is one example of an immunogenetics service.

ET/VT result analysis: Refers to the receipt, comparison, and management of ET/VT results. This could include coordination of VT result transmission between registries and transplant centres, comparison of ET/VT results with registry/CBB typing, updating registrant/CBU typing with higher resolution HLA results, facilitation of HLA typing discrepancy resolution, and/or match level assessment of graft/recipient pairs.

Infectious Disease Marker (IDM) analysis: Review of IDM test results obtained from a fresh donor blood specimen and/or maternal and CBU IDMs performed at CBU banking. IDM sample collection is often concurrent with VT sample procurement and is used to determine suitability and/or safety of a potential graft based on previous exposure to microbial pathogens.

Graft recommendation: Presentation of one or more suitable donor(s) or CBU(s) to the transplant centre for consideration for transplant. HLA match level, non-HLA factors, and test results obtained during formal search will inform graft recommendations.

Graft selection: Final decision of donor or CBU to be used for transplant. Workup, comprising the final stages of testing and clearance prior to collection/procurement, is then initiated with the chosen graft.

Domestic patient searches: Allogeneic HSC searches performed on behalf of patients by their national registry and excluding those performed on behalf of international centres.